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ABSTRACT

An Attendant Care Pilot Project, administered by the Home Care Service of New South Wales, Australia, and providing attendant care for 24 permanently severely physically disabled adults for 2 years, was evaluated. The patients were medically stable and intellectually capable of managing their own affairs; all had impairments which required assistance in personal care, locomotion, and dexterity. Two models of care were tested in the project; and while eight of the patients used attendant care service arranged by the Home Care Service, 16 patients received a regular allowance to arrange such services for themselves. Such issues as the assessment procedures, hiring and training of assistants, insurance, payment of attendants, attendant management, integration with other existing services, costs, and estimates of potential numbers of users of attendant care in Australia were examined. Among the many recommendations were: (1) that a national attendant care program be introduced for severely physically impaired adults; (2) that an attendant care scheme provide an integrated range of services comprising personal and household tasks; (3) that an attendant care scheme provide both of the models for attendant care evaluated in this study; (4) that assessment procedures be adopted to determine the amount of attendant care required; and (5) that a government department be responsible for the administration and assessment of the attendant care scheme. Extensive appendices include questionnaire and interview forms, pilot study survey instruments, ability profile forms, the list of organizations and institutions contacted or visited, the attendant management manual, sample advertisements used to find attendants, and a research brief. A 9-page reference list is also provided. (CB)

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Department of Community Services

EVALUATION OF THE ATTENDANT CARE PILOT PROJECT

Anne Clark and Jean Faragher

University of Sydney
Department of Community Medicine

Final Report to the
Department of Community Services

EC190282

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FOREWORD

This attendant care pilot project has its origins in activity generated during the International Year of Disabled Persons in 1981. One of the many key issues raised at that time was an interest in finding new ways of meeting the personal care needs of people with severe disabilities. The attendant care pilot arose from this interest.

The completion of this report represents two years of very practical social research involving 24 people with severe disabilities who volunteered to take part in the project to assess how viable certain attendant care schemes might be.

The participants in the study were prepared to have their daily lives closely monitored over a two year period to examine the operation of two different modes of attendant care delivery and to identify the practical problems and difficulties associated with meeting the self care needs of people with severe disabilities here in Australia. I am pleased that the Commonwealth Government was able to fund such an undertaking and I appreciate the generosity of the participants in making the study possible.

The information contained in the report will be useful background for everyone concerned with enabling people with severe disabilities to live in the community away from institutions. To the extent that it identifies problems and highlights barriers to the provision of attendant care, it challenges us to come up with solutions.

I certainly hope that this kind of project and resultant reports will lead to greater understanding of the everyday living needs of people with disabilities and a better appreciation of the ways in which governments at all levels might intervene to provide appropriate services to them.

The report will be closely studied by my Department of Community Services and by the recently established Office of Disability.

My thanks go to the researchers from the University of Sydney for producing this report, to the Home Care Service for their key role in provision and co-ordination of the attendant care and to the members of the Steering Committee for their valuable input and suggestions.

Don Grimes

Senator the Honourable Don Grimes
Minister for Community Services

PREFACE

The Attendant Care Pilot Project was established early in 1983. Professor Gary Andrews of the Department of Community Medicine, University of Sydney, based at Westmead Centre accepted the contract to evaluate it, and established the evaluation team at Westmead. In July 1983 Professor Andrews resigned to move to South Australia, and I took over responsibility for the evaluation contract. My involvement has not been onerous. The evaluation team has functioned effectively and efficiently, requiring a minimum of assistance with their task whilst at the same time being very open to discussions and suggestions.

As this report makes clear, neither the pilot project nor its evaluation proceeded entirely as initially planned. Whilst in one sense this may seem to be a disadvantage, in that a controlled trial did not eventuate, in another the descriptive evaluation seems quite appropriate to the topic, in which personal variability is a key issue. The results make it clear that flexibility of lifestyle and enhanced options for living are the most important elements of improved quality of life which arise from good attendant care for the disabled.

I hope that this report will help achieve more readily available, flexible, sensitive and caring attendant care programmes for disabled people in Australia, enabling them to exercise more nearly normal control over their own lives and their chosen contributions to our community life.

C. Bridges-Webb
Professor of Community Medicine
and Head of Department,
University of Sydney

Attendant Care Pilot Project
Steering Committee Members

Ms L. Alsop (to 17.4.84)	Disabled People's International (Australia)
Dr J. Elias	Policy Co-ordination Unit, Community Services Portfolio
Ms J. Ellis	Home Care Service of NSW
Ms M. Foley (to 5.10.84) Ms S. Burns (from 10.9.85)	Department of Health, NSW
Mr R. Llewellyn	Disability Advisory Council of Australia
Mr B. Newton	Disabled People's International (NSW)
Mr D. Roden (to June 1984)	Handicapped Person's Bureau, NSW Department of Youth and Community Services
Mr D. Hall (to 18.8.83) Mr M. Shepherd (6.12.83) Mr D. Limbrick (5.10.84) Mr J. Galvin (from 10.6.85)	Department of Community Services
Mr L. Watts	Acrod

Management Committee Members

Ms L. Adamson	Commonwealth Rehabilitation Service, Department of Community Services
Ms A. Clark	University of Sydney, Department of Community Medicine
Ms D. Percy (to 30.9.84) Ms C-m. Bennett (from 31.10.84)	Home Care Service of NSW

Evaluation Team

Professor G. Andrews (to 31.7.83)

Professor Charles Bridges-Webb (from 1.8.83)

Ms Anne Clark (from 1.8.83)

Ms Jean Faragher (from 1.11.84)

Ms Tania Rtshiladze (Secretary to 13.6.85)

THE PARTICIPANTS

M. Allport
G. Batterham
D. Bell
K. Byrne
I. Cooper
B. Epthorp
K. Ferris
B. Flint
P. Harding
J. Hetherington
M. King
P. Mahony
T. Parkes
M. Shulz
G. Spurway
D. Stabback
R. Street
B. Teakle
and six others

Acknowledgements

We have in the preparation of this report sought and received the assistance and advice of a large number of individuals and agencies. To all those involved in this way we wish to express our thanks.

The twenty four participants in the pilot project deserve special acknowledgement for they willingly gave considerable time and information to the evaluation team. Always showing their awareness of the research nature of the scheme, they made themselves available at times which may not have always been convenient to them, to provide details in both oral and written form. The degree to which they were all prepared to disclose personal information was appreciated and with their consent has been variously incorporated into the report.

Two other groups similarly permitted the evaluation team the courtesy of extensive interviews; these included people receiving personal care from the Home Care Service of New South Wales and some who have arranged to purchase their personal care on a private basis. We greatly appreciated their confidence and assistance.

Many organisations, Government and University departments and their representatives assisted us by way of providing information and advice. We would particularly like to thank: The Home Care Service of New South Wales, (Head Office and branches); The Sydney Home Nursing Service; NSW Society for Crippled Children; Multiple Sclerosis Society of NSW; The Spastic Centre of New South Wales; Paraplegic and Quadriplegic Association of New South Wales; Australian Quadriplegic Association; ACROD; DPI; Royal Alexandra Hospital for Children; Royal North Shore Hospital; The Prince Henry Hospital; Ferguson Lodge; Ashton House and Kimberley Lodge.

To Lynne Adamson, Carmen-mary Bennett (of the Management Committee), Steering Committee Members and colleagues, particularly Tania Rtshiladze, who offered assistance, comment, criticism and encouragement, our grateful thanks.

Special thanks goes to Tim Philips who acted as a consultant in the preparation of the costing information, Lynne Adamson who as the project's Occupational Therapist prepared the section on assessment, and Peter Colville whose assistance in the selection and use of a suitable assessment instrument was greatly appreciated.

We are grateful for the continued encouragement and advice offered by Professor Charles Bridges-Webb to the evaluation and for his critical review of the final report.
Any errors or omissions are, of course, our own responsibility.

A. Clark
J. Faragher

Summary

Overview, Conclusions and Recommendations

The following evaluation of the Attendant Care Pilot Project was commissioned by the Department of Community Services. It should be noted that Attendant Care is not a medical service, nor should it be seen as a replacement of such services.

An Attendant Care Pilot Project, administered by the Home Care Service of NSW, has provided attendant care for 24 permanently severely physically disabled adults of working age for a period of two years.

Each participant has impairments to both upper and lower limbs resulting in functional disability in the areas of personal care, locomotion and dexterity. Survival is dependent on care provided by others. All must use wheelchairs for mobility. The severity of disability is such that the majority (20) cannot propel a manual chair 100 metres. At the most severe level are three people who require complete assistance with eating. At the time of joining the pilot project, some were living in institutions (in nursing homes or in a group home) and others had previously lived in institutions for an extended period of time. All participants were assessed as eligible to occupy a bed attracting the Federal Nursing Home Subsidy.

The pilot project was restricted to examining the attendant care needs of severely physically disabled people aged between 16 and 65 years who are medically stable and who have the intellectual capacity to manage their own affairs. No conclusions, therefore, can be drawn from this study about the appropriateness or otherwise of attendant care for other categories of people.

The numbers in the study were small and as such, while indicating a range of needs, may limit the extent to which they may be taken as representative of the non-aged severely physically disabled population as a whole, in terms of physical dependence, family structure or socio-economic status.

The research brief specifically required the evaluator to not only draw conclusions from the evaluation, but also to make "recommendations regarding the creation of a national scheme" (Appendix H). To the extent that this is possible on the basis of conclusions drawn from a descriptive study of 24 people living in one Australian city and from information presented concerning a somewhat larger number (approximately 200) of personal care users of an existing service agency in the same city (Section 8), recommendations have been formulated and are presented together with the relevant summary and conclusions pertaining to each of the major aspects of Attendant Care.

Two models of care were tested in this pilot project. Eight (8) people used attendant care service arranged by the Home Care Service of NSW and 16 received a regular allowance to arrange such services for themselves.

A summary of conclusions and consequent recommendations made following our evaluation of the Pilot Project are presented below.

(i) Creation of a National Attendant Care Scheme

Improvements in quality of life during the pilot project period have been documented for individuals in some aspects of their lives as measured. The major improvement was having the freedom to choose where and with whom to live. Desired changes in living arrangements were made possible for eight people and undesired changes (which in the absence of attendant care could have been necessary when previous carers suffered a decline in health, died or moved away during the pilot) were prevented for four others. (Section 6.4.1.1)

The percentage of people reporting dissatisfaction with health and personal care, relationships with relatives and close friends, sexual relationships, study cpportunities, understanding of self, participation in hobbies and active recreation and with their perceived degree of independence, decreased over the period of the project. More importantly, the percentage of people reporting dissatisfaction in areas rated as important to them, declined for six of the eighteen dimensions rated. (Section 6.4.2)

Other household members living with some participants, experienced improvements in their own lives. (Section 6.4.2.3)

People previously dissatisfied, because of limited control over arrangements, with care provided through a service agency found their control greatly increased when in receipt of an allowance. (Section 6.4.2.3) These improvements in those aspects of life specifically related to personal care assistance, an aspect of life which for some may occupy as much as one third of waking hours, are of extreme significance for those with servere physical disabilities.

Improvements were not noted in other areas such as self concept, marital status or employment status (general community unemployment levels were relatively high during the pilot period).

The costs to government associated with community living with attendant care and with living in nursing homes, the only existing form of institutional care viable for those with severe physical disabilities, were compared. For the majority of participants, care of the type provided by the Attendant Care Pilot Project, is a less costly alternative to government in terms of unit costs, than the cost of the subsidy that would be payable if they were living in a nursing home. It is recognised, however, that the total cost to government if an attendant care scheme were introduced for people meeting this project's eligibility criteria, would be greater than the current cost to government of providing care for that proportion of the eligible group occupying nursing home places at present. (Sections 7.6, 9.2)

Commonwealth and State governments currently contribute towards the costs associated with community living for those with severe physical disabilities by way of the Domiciliary Nursing Care Benefit (a cash payment), the carer pension (a pension available to a carer not eligible for any other pensions or benefits), domiciliary nursing services and home help services. These existing services do not meet the attendant care needs of this group at the level and in the manner necessary to enable independent living in the community, due to structural characteristics of the services and current budget sizes. (Section 8).

Attendant care, as implemented in this project in both service and allowance forms was found to be a practical method for meeting the care needs of participants. Sufficient numbers of people were available to work as attendants for the rate of pay offered; they were capable of performing the required tasks with training and direction from participants; they were sufficiently punctual and stayed in the job long enough to allow a workable system. The hours available, between the upper and lower limits set for the project proved sufficient to meet the attendant care needs of all except one participant.

Policy questions have been raised in relation to the cost of workers' compensation insurance in the allowance model, the eligibility of relatives to be employed as attendants and varying the amounts included in allowances for reimbursements to attendants for their travel. (Section 5)

The following recommendation is therefore made, assuming that government may be willing to accept responsibility for a greater proportion of the cost of the care of the non-aged severely physically disabled population, than it has in the past.

Recommendation: That a National Attendant Care Scheme be introduced, as an addition to the range of services already available, for people meeting pilot project eligibility criteria, ie, severely physically disabled people aged between 16 and 65, medically stable and with the intellectual capacity to manage their own affairs.

Whilst this study cannot draw conclusions about the appropriateness or otherwise of attendant care for other categories of people, it is pertinent to note that 8.4% of the quadriplegic members of the Paraplegic and Quadriplegic Association of NSW are over the age of 60 years.

Recommendation: That in due course, consideration be given to investigating the eligibility for participation in the scheme of other categories of people, particularly those with the same disabling conditions as pilot project participants but who are over the age of sixty-five years.

(ii) Defining Attendant Care

Attendant care was defined for this project as the provision of assistance with key personal care tasks. Attendant time to be provided was assessed on the basis of personal care needs only (assistance with eating, showering, dressing, bowel and urinary care, grooming, health/hygeine, skin care, transfers, posture, turning and pressure relief). (Section 4.3.2)

Participants also required assistance with normal household chores such as cooking, washing, ironing and cleaning. This assistance was to be provided on a voluntary basis by other household members or by the Home Care Service of NSW through their normal service.

Process data indicates that many participants integrated personal care and household chores in their use of paid attendant time. This was possible within the time allocated for personal care only, when by mutual agreement, household members voluntarily supplied some of the personal care thus 'saving' some attendant time which was then used for other necessary household tasks or when such tasks were carried out by attendants during time which otherwise would have been spent waiting (eg. during a bowel routine) or was part of a minimum time allocation. Integration of personal and non-personal care tasks was found to be the most practical and efficient use of attendant time. (Section 5.1.11, 5.2.4, 4.3.2)

Recommendation: That an attendant care scheme provide an integrated range of services comprising personal and household tasks for which assistance is necessary.

(iii) The Models of Attendant Care

There has been an expressed need for both service and allowance models of care. It is not necessary to establish 'deficiencies' in either model as a means of justifying the need for the other. Evidence is presented that a small but significant proportion of the people interviewed would prefer to have an agency assist them in the management of their attendant care. (Sections 5.1.13, 5.2.9, 8.1.6.5)

The pilot project provided people in receipt of an allowance, with the opportunity to demonstrate that they are capable of managing their own attendant care arrangements at a lower hourly cost than the agency provided services. (Section 7.2.1, 7.2.2)

Recommendation: That an attendant care scheme make provision for two models of care:

- **an 'allowance' or direct payment to the individual.**
- **'service' via an accredited agency for those who elect to have assistance with the organisation and payment of their attendants.**

(iv) Assessment

Assessment was required to determine eligibility in terms of the criteria established for the pilot project and to determine the attendant time to be allocated to each individual.

The Barthel Self Care score (derived from the Colville Ability Profile) was found to be an appropriate indicator of disability in functional terms. Each participant was assessed in the prescribed manner (NH5 approval) as being eligible to occupy a bed attracting the Nursing Home Subsidy. (Section 4.3)

Recommendation: That eligibility for the scheme for this group be linked to a verified functional disability and with eligibility for a Nursing Home place attracting the government Nursing Home Subsidy. Once having established basic eligibility, an individual would be at liberty to select nursing home care or attendant care.

The attendant time allocated (ie, required) could not be accurately predicted from functional status scores. The major factors influencing the amount of paid care required were the amount of voluntary care both available and acceptable and variations in lifestyles (including whether or not the person is employed).

The more experienced allowance group (Allowance 2) required on average, a greater number of hours than the less experienced groups (Allowance 1 and Service). This difference was not due to a difference in functional scores but to differences in social circumstances. (Section 7.6.1, 4.5)

The variation in the number of hours actually used per week was significant and largely reflected varying use of voluntary hours either by choice or necessity (when an attendant was unavailable). Periods spent in hospital, in a nursing home for respite care or on a family holiday also caused variation in the extent of use of paid hours. (Section 5.1.8, 5.2.3, 7.4)

The amount of attendant time required may be assessed most simply by itemising the tasks with which assistance is required, dividing such tasks into those to be done by a household member (to the mutual satisfaction of the disabled person and the household members involved) and those to be done by a paid attendant.

The apparent open endedness of both allocation of hours and subsequent use of hours requires only the establishment of an appropriate ceiling of hours to be made available and a system of reimbursement for hours actually used, in order to provide the necessary controls and safeguards.

Recommendations: That assessment procedures be adopted to determine the amount of attendant care required by an eligible individual, the amount being the difference between the total care required and the voluntary care to be used, ie, attendant hours will be those hours of care not provided by relatives and/or other household members. The amount required can be expected to vary with changes in social circumstances and

occasionally with changes in fuctional level.

That the scheme establish a ceiling of hours available to meet an individual's needs in excess of the hours of voluntary care available and acceptable, resulting in a maximum financial commitment by the Government which is notionally similar to the subsidies payable for nursing home beds.

That people whose total care requirements (voluntary and paid) exceed the 28 hours per week which operated as the upper limit for inclusion in the pilot project, not be excluded from the scheme but be considered eligible to receive up to the maximum hours established for the scheme which would then need to be supplemented with the voluntary labour of relatives and/or friends or with privately paid care as required.

(v) Administration of the Scheme

Continuity of care is guaranteed to those accepting institutional care, once a nursing home bed is secured. Users of existing community care services have no similar guarantee but are directly at risk of reduction in level of service due to increasing competing needs or reduction in budget allocation in real terms. (Section 8)

Recommendation: That the individual (rather than the state or an agency) be the unit for the allocation of resources to ensure sufficient resources to those in need of considerable and continuing hours of care (once allocated) in order to protect such people from changes in budgets or demand for services.

If the individual is to be the unit for the allocation of resources, uniform assessment and reassessment procedures are required.

Recommendation: That a government department with the appropriate Australia-wide infrastructure, be responsible through that existing infrastructure, for assessment and reassessment as required.

Variation in use of allocated hours is likely to occur, even if hours are subject to reduction on the basis of intermittent reassessment (which was not the case in the pilot project). Variation in use in no way invalidates the assessment procedure but suggests the need for a reimbursement process (Section 5). The relatively low incomes of at least a proportion of the users of the scheme suggests the need for appropriate 'starting' grants to begin the cycle of reimbursement. (Section 3.6)

Recommendation: That in the interests of accountability for the substantial sums of money which would be provided, the principle of reimbursement for money spent on attendant care by both individuals and accredited agencies on behalf of individuals be adopted for this scheme. Reimbursement (up to a maximum weekly average), rather than allowances or payments of predetermined amounts, would provide the structure necessary for accountability (whilst retaining the flexibility to vary actual hours from week to week) and could be expected to minimise the amounts required.

That administration of the reimbursement system provide for direct reimbursement to individuals for moneys spent ("allowance" model) and direct billing by agecies on behalf of individuals ("service" model).

The policy questions raised by the pilot project in relation to workers' compensation insurance and travel payments to attendants have been noted previously. Whilst the pilot project had no opportunity to address the possible problems for people living in isolated areas, the significantly greater hourly cost of care for those participants living in the semi rural outskirts of Sydney would suggest the possible need for special provisions under the scheme. (Sections 3, 5.1.3, 5.1.4)

The job characteristics peculiar to attendant work viz shift lengths as short as one hour, relatively greater travel due to shift lengths, out of hours work need to be taken into account when setting the hourly rate of pay. (Sections 5.1.4, 5.2.5, 5.3.2.2)

Recommendations: That suitable Workers' Compensation Insurance be negotiated for the scheme.

That the hourly rate struck for converting assessed hours into dollars, make special provision for isolated areas and take account of the short shifts and travel required in attendant care work but that no separate provision be made for reimbursement for actual travel (HCS of NSW is currently negotiating an award for this type of work).

Disabled individuals and organisations, in the absence of a national attendant care scheme, have sought and secured temporary funding for a variety of attendant care schemes. Consumer control has been an important feature of some of these schemes. (Section 1.3)

Recommendation: That a system of accreditation be introduced for agencies, both public and private, to receive reimbursement for attendant care services provided for eligible individuals. Ideally individuals desiring to use an ageny would have a choice of agencies in their area. Existing attendant care schemes, funded at present in a variety of temporary ways (Department of Community Service's training grants, Employment Initiatives Projects, charitable funds etc) might seek accreditation within the proposed scheme.

Some individuals meeting the proposed eligibility criteria for the scheme would be entitled to other services or forms of compensation (Department of Veterans' Affairs, work or traffic accident related compensation). Care would need to be exercised to prevent the overlap of services and/or entitlements. (Section 3.6) Individuals might be expected to contribute to the costs of their own attendant care (such contributions under current taxation legislation and rulings being tax deductible) on the basis of personal income. (Sections 5.1.2, 3.6)

Recommendation: That if an individual's ability to pay or contribute to the cost of his own attendant care is to be assessed, it be linked to a realistic baseline which recognises the extra costs of disabled living and further, that an individual's contribution, once the baseline is exceeded, be limited to a fixed proportion of excess income in an attempt to avoid the creation of yet another work disincentive for disabled people.

There is a need for a national scheme to ensure the uniform provision of attendant care in all states if equity of access is to be achieved. It is not anticipated nor intended that provision of attendant care would empty nursing homes, nor provide 24 hours per day paid care.

The fragmented nature of existing services across Australia would indicate that if unformity of provision is to be achieved in the future, co-ordination of provision at a federal level would be desirable.

Uncertainty remains regarding the number of Australians who would be eligible for attendant care. Estimates based on a number of different approaches would suggest that between 4000 and 9800 people would be eligible in terms of this project's eligibility criteria. (Section 9)

Recommendation: That policy decisions regarding the funding, control and administration of an attendant care scheme give due consideration to the conclusions and recommendations arising from this pilot project.

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1

INTRODUCTION AND PURPOSE OF THE STUDY

The Attendant Care Pilot Project was funded by the Australian Government to investigate local conditions pertaining to the provision of attendant care for severely disabled people, specifically the size of potential client groups, their particular attendant care needs and how these needs might best be met.

Attendant Care has been, in other countries, a key factor which has enabled many people with disabilities to live normal lives in the mainstream of society, enjoying the independence others take for granted. Care has long been provided by society in institutions, and by relatives and friends in community settings, often at the expense of individual independence. The rise of the Independent Living Movement, initially in the USA and later spreading worldwide, had, by raising disabled people's expectations with regard to normal lifestyles, created a demand for publicly funded attendant care in community settings.

Attendant Care was defined for this project as assistance, provided by an employee to a person with disabilities, with self-care tasks which, were it not for his disability, that person would do for himself. It is not a medical service nor should it be seen as a replacement of such services.

1.1 The Independent Living Movement

The Independent Living Movement is characterised by two main themes; disabled people having self direction and control over their own lives and enjoying full participation in the life of the community.

The origins of this movement have been traced by DeJong (1978) at least back to 1962 in Illinois, USA when four severely disabled students transferred from a nursing home to a modified house close to a university campus. Its association with academic communities continued, notably in Berkeley, California and Boston, Massachusetts where centres for independent living were established in 1972 and 1974 respectively.

Subsequent years have seen a proliferation of independent living programmes, including independent living centres which provide advocacy and consumer services, residential programmes and transitional (or independent living training) programmes, not only in the USA but in other countries as well. Gloag (1985) reports the development of six Centres for Independent Living in the UK

(Derbyshire, Exeter, London (Islington), Manchester, Norwich and Hampshire).

The underlying principle upon which all of these centres and programmes must be based if they are to keep faith with the independent living movement, is a community basis and substantial consumer involvement in the direct or indirect provision of those services necessary to increase self determination and to minimise unnecessary dependence on others. Attendant care is one of those services.

The US 1973 Rehabilitation Act was a watershed for people with disabilities in that it prohibited discrimination against 'otherwise qualified handicapped' individuals 'under any programme or activity receiving Federal financial assistance'. As DeJong (1978) explains, it mandated that those who were most severely handicapped were to receive first priority for services under the Act, that affirmative action programmes for the employment of disabled persons were to be introduced and it established the Architectural and Transportation Compliance Board. Amendments in 1978 established the basis of a grant programme for independent living centres. The significance of this amendment, Verville (1979) comments, is that for the first time a programme for disabled people had been funded which did not have as its primary goal, to help such persons become employable. This acknowledgement of the possibility that employment may not be the only desirable goal for disabled people recognises the plurality of society today.

The movement's constituency, attributed by DeJong (1978) to its association with academic communities, has largely been young (older adolescent and younger working-age adult) and represents only a few major disability groups (spinal cord injury, muscular dystrophy, cerebral palsy, multiple sclerosis and postpolio disablement). This focus has been carried through into the pilot project described in this report, by the government department funding it.

1.2 Attendant Care Programs in other Countries

Despite the enormity of the changes of the last twenty years and the existence since 1978 of Title VII of the Rehabilitation Act, "Comprehensive Services for Independent Living", under which funding could have been allocated, the USA still does not have a major national service programme. This is perhaps not surprising in a country in which traditionally, the states are responsible for the provision of welfare services. Attendant care, one component of such a service programme, is available in most US states in some form (subject to a variety of restrictions) under a variety of funding arrangements. Litvak (1985) in her survey of the provision of attendant care across all US states reports funding under Title XIX - Medicaid (20 states), Title XIX Waivers (20 states), Title XX - Social Services Block Grant (11 states), Title VII - Vocational Rehabilitation (12, but 5 for rehabilitation trainees only), Title III (2 states) and in sixteen states, only state funds are being used. An attendant care allowance is available under some of the funding arrangements.

The picture in the UK is a similar pastiche of funding sources for a range of programmes, providing for the most part, family support or relief care, specifically excluding in some cases those living alone. Crossroads care attendant schemes, numbering thirty by 1979 after first appearing in 1972, are jointly funded by Regional Councils and Health Boards. The scheme is, however, a registered charity, as are the Spinal Injuries Association and the Cheshire Foundation, each now operating care attendant schemes (Gloag, 1985).

1.2.1 Selected Attendant Care Schemes

Sweden

The most comprehensively funded attendant care services appear to be those available in Sweden, these being for use at places of employment, education and residence. The Swedish National Board of Labor reimburses employers for personal assistance provided to disabled employees up to a maximum of 2 to 3 hours per person per day. Personal assistants are provided by schools for disabled pupils, attending their regular neighbourhood schools, the costs being shared 60/40 by local and state governments. A similar provision for tertiary students is completely state funded. Care attendant services at home are integrated with other social services provided by local governments, the type and quality of service varying from one municipality to the next. In some communities home attendants are not available after office hours or during weekends. Ratza (1982) criticises the awkwardness of arrangements when disability is accompanied by a chronic medical condition or where help is required during the night. Counties bear the cost of this type of help, paying for visiting nurses if necessary or for the regular municipal attendants. Some counties provide direct cash payments to consumers to employ relatives, neighbours or others. A non-taxable allowance from the National Insurance, serves the same purpose as the Australian Domiciliary Nursing Care Benefit and the Attendance Allowance available in the UK. None of these allowances is sufficient for purchasing all the care required by persons with severe physical disabilities.

State of Maryland Attendant Care Program (USA)

State legislation (Education Article SS21-S01-21-506) established a pilot programme to provide financial assistance for attendant care services for eligible disabled individuals in fiscal years 1983 and 1984. The Department of Education's Division of Vocational Rehabilitation was authorised to spend $US150,000 in each of those years.

By April 1985, following an independent evaluation (Markowitz, 1985) which was completed by October 1984, legislation was passed to establish a permanent attendant care programme funded at the same rate as the pilot.

The programme provides reimbursement for attendant care services purchased by adults with a severe or permanent physical disability who must be

- employed, seeking employment or on the waiting list for an approved nursing home
- between the ages of 18 and 64 years
- have a yearly income of less than $US26,999 and
- receiving no duplicate services or financial assistance

Applicants must have their doctor or nurse complete an assessment form which identifies the amount of care required in six functional areas (routine bodily functions, transfers, assisting with eating, exercise regime, personal hygiene and household related chores) and must complete an Income Statement (taxable and non-taxable, self and spouse) themselves. Each is a single sheet requesting only the information required. Reimbursement up to a maximum of $US269 fortnightly, being between 95% and 5% of the actual cost, depending on recipient's income, is paid to recipients on the basis of fortnightly timesheets (signed by attendants) and certification of the amounts spent and claimed (signed by recipient). Recipients are responsible for

- selecting, hiring, training and supervising attendants
- paying attendants, including applicable taxes
- maintaining accurate records of hours and days that attendant care services are provided
- preparing and submitting payment request forms
- reimbursing the Department for any overpayment

Recipients may not employ a spouse, child, step child, parent, grandparent, sibling or in-law including a spouse's parent, grandparent or sibling, as an attendant.

An average of 43.74 hours per week was required but the majority of employed recipients required less than 30 hours per week.

The evaluators of the pilot stage recommended an expanded role for the Program Co-ordinator, a position which had been filled during the pilot by a departmental member still responsible for her regular job, to include assessment as well as administration. In addition they recommended the appointment of an Occupational Therapist to the Co-ordinator's position. All recipients felt that an attendant registry, for emergencies in particular, needed to be established.

Medicaid Medical Assistance (federal assistance available in many American states, including Maryland) is known in Maryland as the Personal Care Program. It provides approximately $10 per day which may be paid to an attendant directly or signed over to an authorised agency then responsible for employing and paying attendants on behalf of these recipients. There are currently two such agencies in Maryland, one an Independent Living Centre under the auspices of Maryland Citizens for Housing for the Disabled Inc., the other, the Jewish Family and Children's Service. The ILC policy is to encourage people to make their own arrangements, once they have become familiar with attendant care management. Persons living in the same house as the recipient cannot be employed as attendants.

The authorisation of a variety of agency types increases the choices available to individuals requiring agency assistance with their attendant management.

The In Home Supportive Services (IHSS) Program, California

Established in 1959, this programme is the oldest source of attendant care in the USA, a social rather than a medical service, providing services (domestic tasks, personal care, transportation, yard hazard abatement, protective supervision and teaching (demonstration)) to any low income disabled or elderly person who needs them to remain in their own home. Zukas, Cone and Leon (1984) present a comprehensive descriptive analysis of IHSS. County welfare departments are responsible for the actual delivery of services via three statutorily - permitted methods

- paying individuals hired by the recipient (Individual Provider or IP mode)
- contracting with an outside agency which may be government, non-profit or profit making, to provide services (contract mode)
- using their own employees (county mode).

Severely impaired recipients (i.e. those requiring twenty hours per week or more of certain specified personal care services) are entitled by legislation to hire and pay their own attendants, so all counties use IP mode for at least some of their clients (28 of 58 counties use it exclusively). Thirteen counties in addition use the county mode and sixteen use the contract mode. More than three quarters of all clients use the IP mode. Payment for the IP mode may be directly to the provider (attendant) on the basis of timesheets submitted to the county welfare department or in advance (i.e. an "allowance") to the recipient, if eligible (must be severely impaired) and requesting this method (known as payrolling advance, which must be accounted for by submission of timesheets when attendants have been paid).

The numbers of people using this service are used as a basis for estimating the potential numbers of attendant care users in Australia. Results are reported in Section 9.

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The most common number of hours per week required by the severely impaired clients is 38 to 50 (42%) while a quarter use between 25 and 37 and a quarter use between 51 and 62. The maximum amount payable for severely impaired clients was $US921 per month in 1984.

A county welfare department social worker initially assesses all new applications for service and is required to make "reasonable efforts" to help individuals find an attendant. Recipients are then essentially on their own.

IHSS neither provides nor requires training for recipients or attendants but counties and contract agencies may have their own internal requirements.

Separately financed independent living programmes, consumer based and operated, provide assistance to IHSS recipients on all aspects of attendant recruitment, screening, training, referral and management if required.

A spouse or parent may receive payment for attendant care services if the provision of those services forces the person to leave or not enter full-time employment (13% of the attendants working for severely impaired recipients, fall into this category).

New Zealand Attendant Care Program (Pilot), Auckland (1983 - 1985)

This recently completed two year pilot, funded by the Department of Social Welfare and set up by the Auckland Crippled Children's Society, provided up to twenty hours per week per client, initially for people aged 16 to 64 but later extended to include older people. After one year of operation 50% of the 78 clients accepted were aged over 65 years. The decision was made at that time, given the original aims of the scheme, to accept no new clients aged 65 years or over for the remainder of the pilot. The agency 'links' disabled clients and attendants, retaining responsiblity for paying the attendant but giving clients the final say in their selection and management. The most common disabling conditions were multiple sclerosis, arthritis, stroke and dementia with the majority of clients receiving 6 to 10 hours per week. Notably absent from the client list are people with spinal injuries.

1.3 Developments in Australia

Whether the American Independent Living Movement was instrumental in initiating change in other countries or whether the general social and cultural milieu of many developed countries in the sixties and seventies gave rise to simultaneous but separate stirrings is not clear. The significance of medical and technological advances in the fifties and sixties on the survival rate of those with severe spinal injuries should not be overlooked in this regard. Their articulation of their unwillingness to accept an enforced reduction in their personal independence added strength to the press for change.

Our society mandates, through its legal and medical statutes and practices, that people with severe disabilities will survive and be rehabilitated; some would claim that it therefore behoves that society to make adequate provision to enable such people to exercise their "... right to enjoy a decent life, as normal and full as possible." (United Nations Declaration on the Rights of Disabled Persons, 1976). Institutional care, the only adequately public-funded (some would dispute the adequacy) living arrangement presently available, does not, some would claim, enable a 'normal' life and, as experiences in other countries have shown, is not the only possible option.

Regardless of origins, the independent living movement in Australia had reached a peak by 1981, the International Year of Disabled Persons.

Encouraged by the American experience in particular, in the successful establishment of publicly funded attendant care services, disabled individuals and organisations in Australia explored all possible avenues for funding such services. By 1981 some care was being obtained in some areas via grants for specific projects from the Department of Social Security or through an expansion in the scope of services offered by existing home help agencies in response to active lobbying by disabled individuals.

These were seen for what they were, interim solutions to meet a pressing need, not necessarily providing the level of assistance or degree of control so necessary for independent living.

People with disabilities and their representative organisations in Australia, influenced by the philosophies and success of the independent living movement, long dissatisfied with the roles and lifestyles to which society had relegated them, began campaigning in earnest in 1980 for the introduction of a National Attendant Care Scheme.

The sequence of events which culminated in the announcement of the funding of this pilot project included:-

ACROD, the Australian Council for Rehabilitation of Disabled, prepared in July 1981, in consultation with individuals and organisations nationwide, a proposal for a National Attendant Care Allowance detailing the case concerning the need for attendant care services for disabled people in Australia and consequently the need for an Attendant Care Allowance.

The NSW Advisory Council on the Handicapped recommended to the NSW Minister for Youth and Community Services in 1981 that

- the concept of a National Attendant Care service be supported in principle as a means of promoting the normalisation of lives of sensorily handicapped people
- Attendant Care be accepted as a necessary part of adequate income security measures, therefore a Commonwealth responsibility
- a pilot Attendant Care scheme be undertaken jointly by the Commonwealth and the States to assess costs and needs, with Commonwealth funding.

Recommendations were made to the Minister for Social Security by Acrod in January 1982, that an attendant care allowance be introduced and that such an allowance should be paid to mentally, physically or sensorily disabled people who are dependent on others for assistance in the areas of essential personal care.

The National Advisory Council for the Handicapped submitted a proposal for an attendant care allowance, to the Minister for Social Security in July 1982.

In response to these representations an amount of $100,000 was earmarked from the funds allocated for the Handicapped Persons Welfare Programme Upgrading in the 1982/83 Federal Budget, to carry out a pilot project to investigate alternative modes of providing attendant care assistance. Provision was made in the 1983/84 and 1984/85 budgets up to an overall total of $600,000 to continue the pilot project for a two year period. The pilot was to be evaluated by an independent body.

New Directions, Report of the Handicapped Programs Review (1985), prepared by the Secretariat established by the Minister for Community Services (formerly Minister for Social Security) to review services and programmes provided by his department for disabled people, included acknowledgement of the need for attendant care and the recommendation that it be introduced in both service (under the proposed Home and Community Care legislation) and allowance modes (to be included in a Disability Allowance which "in time" would include a component for attendant care). Information available from this pilot study will be used to determine the details of an attendant care scheme, not to establish the need for one.

1.4 Evaluation of the Pilot Project

1.4.1 Aims of the Evaluation

The aims of the evaluation were specified by the funding body in a Research Brief (see Appendix H). The evaluation group was directed to address the following aspects of the pilot, in terms of its objectives.

Objective 1: Analyse whether attendant care is the only missing key to independent living for severely disabled people

- document the barriers to independent living by a lack of support or incentives required to overcome these problems
- measure the gains participants make in independent living capacity

Objective 2: Gather information about the process of providing attendant care and the possible forms in which it could be provided

- comparison of advantages of service and allowance based modes for people with different levels and types of disability
- document a critical review of the pilot including such matters as;
  - i) how attendants are recruited and trained
  - ii) characteristics of attendants and turnover rates
  - iii) formal and informal activities by the co-ordinator and proportion of time spent on each major activity
  - iv) reliable assessment scales and indices of independent functioning
  - v) the most appropriate mechanisms for assessment
  - vi) any changes that occur in assessment and administrative procedures
  - vii) clients' satisfaction with assessment and service delivery
  - viii) any variation in the level of attendant care needed by participants according to living arrangements

Objective 3: Measure changes in quality of life experienced by participants and compare costs associated with institutional and community living.

1.4.2 The Target Population

The research brief directed that the target population for this pilot was to be "severely handicapped people requiring between two and four hours per day of assistance with key personal care tasks such as bathing, dressing and toileting (within) the broad working age group and having reasonably stable medical conditions. High priority will be given (to those) in employment or vocational training or those who have reasonable employment prospects".

The Steering Committee subsequently modified this definition to restrict the target population to those severely disabled individuals with the intellectual capacity to manage their own affairs and with a reduced emphasis on the employment criterion. "Reasonably stable medical conditions" was to be interpreted as referring to an individual's short term prognosis i.e. for the duration of the pilot.

The target population for the pilot project therefore comprised all persons aged between 16 and 65 years, who have a severe personal care handicap, such that at least two and not more than four hours assistance per day is required for personal care, who have the intellectual capacity to manage their own affairs, and with reasonably stable medical conditions. Preference was given to persons in employment, training or with reasonable employment prospects.

1.4.3 Definition of Attendant Care

Attendant Care, for the purposes of the pilot, was defined as assistance with key personal care tasks such as bathing, dressing and toileting.

1.4.4 Evaluation Design

The pilot trialled government funded personal care in non-institutional settings for persons who cannot or do not want to have their personal care needs met by family members. The two options trialled were a personal care service and a personal care allowance.

The evaluation design was based on a maximum possible sample size of 24, determined by the size of the budget and restricted by the fact that this sample comprised people selected from a group of 48 volunteers. The presence of an alternative source of personal care in the city in which the pilot was to operate precluded the possibility of a control group.

The evaluation is a descriptive analysis of the pilot's organisation and its participants, comparing the two models of care, describing changes in the quality of the participants' lives during the pilot and examining the costs associated with the provision of attendant care, specifically those costs to be met by government. The costs associated with an alternative form of care provision, nursing homes, are also examined.

The organisational or process factors described separately for each model include

- assessment procedures
- hiring and training attendants
- insurance
- payment of attendants (including travel reimbursement)
- attendant management
- integration with existing services
- costs
- estimates of potential numbers of users of attendant care in Australia

An existing provider of personal care services, the Home Care Service of NSW is described on the basis of information obtained by a survey of Branch co-ordinators and interviews with a representative sample of clients, to provide a broader base from which to draw conclusions about the provision of a personal care service and the potential numbers of users of such a service.

2

OPERATIONAL HISTORY OF THE PILOT PROJECT

Funds having been allocated in the 1982/83 Federal Budget, as outlined in Section 1, the Attendant Care pilot came into existence with the appointment, by invitation, of representatives to a National Steering Committee. The committee's role was to monitor the implementation of the project and advise the Minister of Social Security (later, the Minister for Community Services) on its progress.

Contracts were let, in June 1983, to the Home Care Service of NSW to implement the pilot and to the University of Sydney's Department of Community Medicine, to evaluate it. The Department of Social Security's Commonwealth Rehabilitation Service was to provide the staff for an assessment unit.

The Steering Committee, at its meeting on 18 August, 1983 appointed a Management Committee, comprising the Pilot's:-

Co-ordinator (HCS of NSW),
Occupational Therapist (Department of Social Security)
Evaluator (University of Sydney)

to oversee the day to day operation of the pilot. The Management Committee met for the first time on September 12, 1983.

A joint press release was made by the Federal Minister for Social Security and the NSW Minister for Youth and Community Services on October 7, 1983 when advertisements calling for applicants to participate in the study appeared in many major and minor Sydney newspapers.

Offers of places in the pilot were made in late December, 1983 with the actual commencement of attendant care for some participants by mid-January, 1984.

Significant dates for this establishment phase were:-

August 1982	Funds allocated in the Federal budget (within the Handicapped Persons Welfare Programme Upgrading funds) for the Attendant Care Pilot Project
December 1982	Invitations to nominating bodies to accept membership of a National Steering Committee

	Invitations to researchers to express interest in evaluating the pilot
February 1983	Offer of research contract to University of Sydney and implementation contract to Home Care Service of NSW
June 1983	Contracts signed by Home Care Service of NSW and University of Sydney
August 1983	Occupational Therapist (DSS) and Evaluator (University of Sydney) appointed
September 1983	Co-ordinator (HCS) appointed
October 1983	Advertisements for participants
December 1983	Offers of places
January 1984	First participants commenced receiving Attendant Care

2.1 Pilot Design

The practical details of pilot implementation were determined by the Management Committee within the constraints imposed by the evaluation design. Modifications were necessary from time to time in response to suggestions from participants and in the light of experience.

The pilot, as it was implemented, is described in Section 5.

2.2. Publicity

The Management Committee members undertook an intense programme of visits to institutions and organisations providing services of any kind for people with severe physical disabilities in the Sydney area, both to familiarise themselves with the Sydney context and to disseminate information about the pilot as widely as possible. Nursing homes, hospitals, rehabilitation centres, an independent living centre and a hostel were all visited, as were some organisations of the disabled. Any 'major organisation' not actually visited, was contacted by phone and sent written information. Domiciliary nursing organisations in several areas were also visited. A complete list of the organisations and institutions contacted and/or visited is included in Appendix A.

Three organisations, the Paraplegic and Quadriplegic Association of NSW, the Australian Quadriplegic Association and the Spastic Centre of NSW, advised appropriate members, in writing, of the existence of the pilot, inviting applications.

2.3 Advertisements for Volunteers to participate in the Study

Advertisements calling for applications from people with severe physical disabilities interested in taking part in the study were placed in major and minor Sydney newspapers and in journals published by organisations of the disabled on and about October 8, 1983. Efforts were renewed in the weeks following, when it became apparent that earlier advertisements were attracting few applications. Radio, television and newspaper coverage was sought both directly through media organisations and indirectly through the Media Liaison Officer of the Department of Social Security in Sydney. Applications, originally scheduled to close by the end of November, remained open for three and a half months not finally closing until January 31, 1984.

2.4 Initial Interviews

Fifty two people enquiring in response to the advertisement and meeting the basic age and severity of disability criteria were interviewed in person. The numerous enquiries received on behalf of elderly people were directed to existing community services.

Forty nine people interviewed, completed a formal application form, one of which was subsequently withdrawn. There were thus forty eight final applications to participate in the pilot. The application form is included at Appendix B.

2.5 Selection of Participants

Thirty seven applicants met the requirements of age, medical stability, functional level (ascertained at this stage without detailed assessment) and employment status, (revised criterion). The pilot budget, being a fixed amount of $600,000 for a 2.5 year period (including evaluation but not assessment component), determined the total number of attendant hours available and hence the number of participants who could be selected - (24). Eleven applicants did not meet all requirements and were thus not considered for selection. The reasons for rejection are given in Table 2.1. It was considered inappropriate to include those applicants who were completely satisfied with their current paid attendant care arrangements (from Home Care Service of NSW) in that much of the impact of the provision of attendant care may have been experienced already.

Table 2.1: Reasons for Rejected Applications

Reason	Number of applicants		
	Males	Females	Total
Not meeting employment criterion	3	1	4
Not at maximum functional level	1	0	1
Not medically stable	1	0	1
Completely satisfied with current care	3	2	5
Total	8	3	11

More than half of the applicants had been receiving paid personal care assistance already, making impossible the selection of 'naive' subjects (in the research sense) for the service and allowance groups.

The compromise accepted was the formation of three groups with eight, seven and nine subjects respectively. Two groups, a service and an allowance (Allowance 1), were inexperienced with respect to paid personal care while the third group, a second allowance(Allowance 2), comprised people who had previously used paid care. Preferences for service or allowance expressed by inexperienced people were taken into account. Matching in terms of age, marital status, reason for wanting attendant care, disabling condition, length of time disabled, highest educational level attained, current living arrangements, occupation and nature of income was attempted, the result being far from satisfactory. The limited number of volunteers meant accepting this situation.

In summary, neither random allocation nor matched groups was possible in selecting these participants. The selection of a control group who would not receive paid care was precluded by the expectation that applicants not selected to receive care would seek assistance from the Home Care Service of NSW. Subsequent events vindicated this expectation.

Places in the pilot were offered to seventeen people on December 20, 1983, from the forty acceptable applications which had been received at that time. All accepted.

A further seven offers were made on February 3, 1984, four from the eight new applications which had been received in the meantime and three from the original applicants, all of which were accepted. One acceptance in this group of offers was later withdrawn before any attendant care had been received. Applications were re-opened in the hope of receiving more applications from persons currently residing in institutions. Two such applications were received and the final offer of a place to fill the vacancy left by the withdrawn acceptance, was made on August 6, 1984.

The characteristics of the group finally selected are presented in Section 3.

2.6 Functional Assessments

The occupational therapist assessed the abilities and personal care needs of each participant by personal interview either at home or in the nursing home in which applicant was living at that time, in December 1983. Reassessment was available on request at any time and was carried out routinely for all participants in

June/July 1984,
December/January 1985
July/August 1985

to monitor possible changes.

2.7 Commencement Dates

The actual dates on which participants commenced using attendant care provided under the pilot were dependent on a variety of factors including availability of suitable accommodation, selection of attendants, current medical condition and when offer of place was received. Dates ranged from January 1984 to March 1985.

The month of commencement and reasons for not starting in January/February 1984, where appropriate, are shown in Table 2.2. The four people who commenced after June 1984 were all moving out of institutions and encountered delays arranging accommodation.

Table 2.2: Commencement Dates of Participants in the Project

Month Commenced	Number of participants Allowance (n=16)	Service (n=8)	Reason for late start
1984			
January	5	0	
February	6	5	
March	1	0	Selecting attendants
May	0	1	Late offer (Feb '84)
June	1	1	Late offers (Feb '84) and medical problems*
July	1	0	Indecision re leaving a nursing home - already owned a house
September	1	0	Later offer (Feb '84) and accommodation
December	1	0	Later offer (Aug '84) and accommodation
1985 March	0	1	Accommodation and finding people to share house

* Both had sustained spinal injuries relatively recently, were just completing rehabilitation programmes and had medical problems to be dealt with (kidneys, calcification of hips).

2.8 Schedule of Evaluation Interviews

1984 January/February	Quality of Life No.1 - Participants
April/May	Home Care Service of NSW Branch Co-ordinators
June/July	Follow up interviews - Participants
December/January	Quality of Life No.2 - Participants
1985 February/March	Costs of Disabled Living - Participants
April/May/June	Home Care Service of NSW - Disabled clients Private paying group - Costs of Disabled Living
September	Quality of Life No.3 - Participants

2.9 Schedule of Formal Training Sessions

January 1984	Allowance Participants - Attendant Management Workshop
February 1984	Allowance Participants - Attendant Management Workshop
April 1984	Service Attendants - Safe Lifting Techniques
February 1985	Service Attendants - Sharing experiences and planning training
March 1985	Service Attendants - Orientation for a group of new attendants
June 1985	Service Attendants - Spinal Injuries
July 1985	Service Attendants - Safe Lifting Techniques

2.10 Changes in Management Staff and Participants

1. The pilot's first Home Care Service Co-ordinator resigned to take up a new position on 30 September, 1984.

   The occupational therapist, with the assistance of a part-time book-keeper, accepted responsibility for the day to day management of the pilot until the new Co-ordinator took up duties on 31 October, 1984.

2. One allowance model participant withdrew in January 1985 (six months after commencing) largely because he did not like the intrusion into his life which was necessarily required by a research study.

2.11 Termination of the Pilot

Benefits to all participants, irrespective of when they started, were due to cease in February 1986. Additional funding was made available under a new agreement for a further six months, to enable a thorough study of this evaluation report to take place. The information included in this report however, pertains to the period between September 1983 and October 1985.

3

KEY CHARACTERISTICS OF THE STUDY GROUP

Twenty four people with disabilities took part in the Attendant Care Pilot Study. The way in which they were selected has been described in Section 2. They do not live close to each other but in suburbs scattered all over the greater Sydney metropolitan area, from Campbelltown in the South West, to Box Hill in the north west, Dee Why in the North East and Kogarah in the South. Some live in old established densely populated suburbs while others live in semi-rural suburbs on the city fringe where the typical property is 2.5 hectares (see Figure 3.1), and the population densities correspondingly lower.

The only characteristic common to every member of the group is in fact their disability. Each has impairments to both upper and lower limbs resulting in functional disability in the areas of personal care, locomotion and dexterity. All are severely handicapped with respect to physical independence and mobility at least, with some experiencing further handicap due to restricted access to work, money and social participation. The terms 'impairment', 'disability' and 'handicap' have been used here with due regard for the WHO (1980) definitions.

Wheelchairs are used by all (four can propel a manual chair 100 metres, nineteen either use a powered chair or propel a manual chair very slowly and one requires assistance) and each member of the group was assessed by a Commonwealth Medical officer of the Department of Community Services' Nursing Home Benefits Branch NSW, as eligible to occupy a bed attracting the Nursing Home subsidy. Twenty two require complete assistance to dress their lower limbs (two can provide useful assistance) and sixteen, complete assistance for upper limbs (seven usefully assist and one requires only prior assistance). Should the need arise, each would receive priority in gaining access to a nursing home bed. Their personal care needs exceed the care which can be provided in hostel accommodation. (Department of Community Services, 1985b.)

Five participants have difficulty speaking clearly (two mildly, one moderate, two severe). One participant is blind. A more detailed account of levels of impairment, disability and handicap is included in the occupational therapist's report on Assessment in Section 4.

Individual differences in coping ability, motivation and a range of socio-economic factors make the relationship between impairment and handicap far from direct.

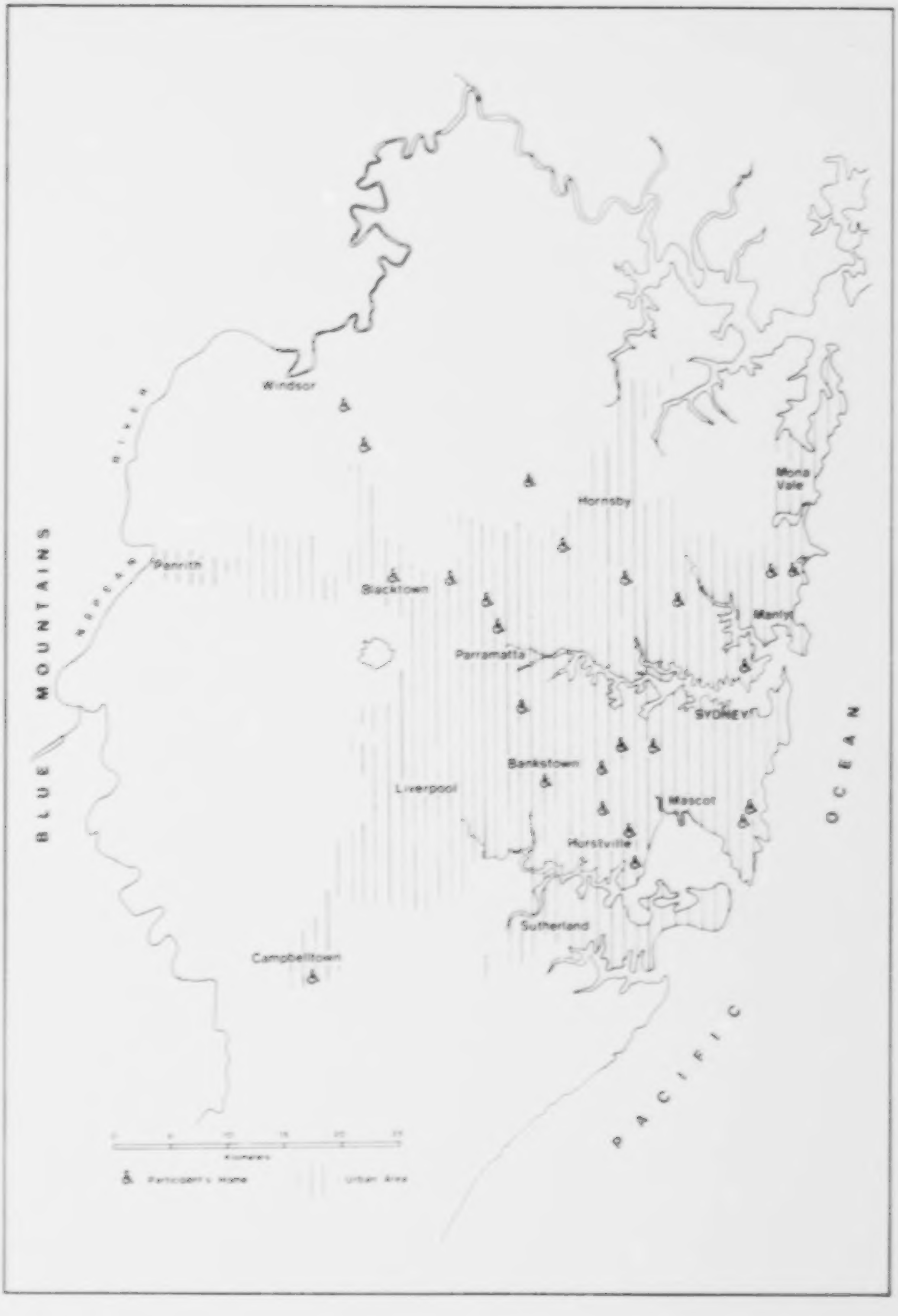
Windsor
NEPEAN RIVER
BLUE MOUNTAINS
Penrith
Blacktown
Hornsby
Mona Vale
Manly
Parramatta
SYDNEY
Bankstown
Liverpool
Mascot
Hurstville
Sutherland
Campbelltown
OCEAN
PACIFIC
0 5 10 15 20 25
Kilometers
Participant's Home
Urban Area

Figure 3.1: Location of Participants' Homes within the Sydney Area

3.1 Reasons for applying to join the pilot

None of the participants in this study could survive without personal care assistance on a daily basis. Personal care is expensive for this group because of the quantity of care required and is beyond their private means to pay. None are willing to accept the government funded care provided in nursing homes, for which they would be eligible, except as a last resort.

Thus the major reason for applying to join the pilot study was to secure paid attendant care services

i) to relieve household members, physically capable of providing the care, from being obliged to do so

ii) to replace the care previously provided by household members who are now no longer physically capable of doing so

iii) to enable the person to leave an institution which they had previously entered as a last resort in the absence of any available care in the community

iv) to enable a person to leave a household in which they had been residing because "free" care was available.

with the overall objective of increasing or maintaining the desired level of independence and quality of life.

3.2 Age and Sex

The group comprised seventeen men and seven women aged between seventeen and fifty seven years, distributed as shown in Table 3.1.

Table 3.1: Age and sex distribution of the participants

Age (years)	Sex		Total
	Male (n=17)	Female (n=7)	(n=24)
16-24	5	0	5
25-34	4	4	8
35-44	7	2	9
45-60	1	1	2

All participants aged thirty five years and over, with only one exception, had become disabled as adults. This partly reflects the life expectancy associated with some congenital conditions but may also be due to a reduced likelihood of the now older congenitally disabled person, who grew up at a time when societal expectations were quite different, viewing independent living as a possibility , particularly if it had been necessary to enter a nursing home as parents aged.

3.3 Disabling conditions

One third of the group were born with a disabling condition while two thirds had become disabled as a result of trauma or disease at sixteen years of age or older.

The spinally injured participants in this study, as a group (n=13) are atypical on two counts; age and type of accident. A recent survey of members conducted by the Paraplegic and Quadriplegic Association of NSW (1984/85) reported that approximately 30% of a representative sample of quadriplegic members interviewed in 1983/84 were aged between 35 and 49 years. Over 60% of the quadriplegic participants in this pilot study were in that age group at that time. Whereas the other surveys report up to 50% of cases of quadriplegia arising from road accidents and 17% from sporting accidents the respective percentages for this group are 30 and 70.

They are not atypical, however, in terms of the age at which their accidents occurred when compared with survey results reported by the Department of Social Security (1977), Dowda (1982) and the Paraplegic and Quadriplegic Association of NSW (1984/85).

The disabling conditions classified by time of onset, are shown in Table 3.2. Only three adult onset conditions had commenced more than twelve years ago. Early childhood onset conditions had been causing disability for between 19 and 36 years, although three did not reach their present level of severity until adolescence, thus reducing their period of severe physical disability to approximately ten years.

Table 3.2: Disabling conditions of Participants

Time of onset	Condition	Number of participants		
		Male	Female	Total
Adult	Spinal injury (quadriplegia)	11	2	13
	Poliomyelitis	0	1	1
	Multiple sclerosis	1	1	2
Early Childhood/ Birth	Cerebral Palsy	2	2	4
	Muscular dystrophy	3	0	3
	Muscular atrophy	0	1	1
Total		17	7	24

Table 3.3: Length of time Participants have been disabled

Period of disablement (years)	Time of onset	
	adult (n=16)	early childhood/birth (n=8)
0-5	7	0
6-10	4	0
11-15	3	0
16-20	1	3
21-25	0	0
26-30	0	1
31-35	1	3
36	0	1

Table 3.4: Age at which Participants became disabled

Age at which disabled (years)	Number of participants (n=24)
0	5
1-13	3
16	1
18-19	4
20-24	5
25-29	1
30-34	3
35	1
47	1

3.4 Household composition and accommodation

A variety of living arrangements was represented in the group at the time they joined the pilot. Seven people planned to change where and with whom they were living because availability of attendant care made the move possible (five leaving institutions, two leaving parents' home).

Ten people were living with their parents, nine in the parents' home and one in his own home. Other relatives (siblings, uncle, son) lived in four of these homes and two mothers were widows. Seven people were living in their own home with a spouse or significant other (six owned, one rented). Other relatives (young children, adult children, mother-in-law) lived in four of these homes. One participant and his fiancee were living in a friend's home.

Of the five leaving institutions three were moving into rented accommodation with friends, one into rented accommodation with spouse and small child and one into his own home in which he had his mother living and which he had been living in at weekends for some time.

Table 3.5: Current accommodation at time of Application

Type		Number of participants (n=24)
Community	Own	10
	Parents	9
Institution	Nursing Home	4
	Group Home	1

Table 3.6: Household composition of Participants

With whom sharing accommodation	Number of participants	
	when applying (n=19)	when leave institution (n=5)
Parent/s only	5	1
Parent/s and other relatives	5	
*Spouse only	4	
*Spouse and dependent children	2	1
*Spouse and adult children	2	
Friend/s	1	3

*The term spouse includes dejure, defacto and 'significant other' relationships.

3.5 Previous source of care

The Home Care Service of NSW had been providing personal care assistance to eight participants for periods varying from two months to four years, at the rate of 9 to 28 hours per week. Other household members, private employees or district nursing had supplemented these hours in all but one case (that being the one receiving 28 hours/week).

Two people had been receiving district nursing at the rate of 10 hours per week (over five days) for approximately 12 months, supplemented in both cases by household members. One person had been employing a private nurse at the rate of 11 hours per week (the maximum she could afford at $400 per month) for about five years, supplemented by a paid housekeeper and an ageing mother. This situation had recently ended when inflation eroded capital which then no longer generated income sufficient to cover nursing costs and the mother returned to her own home inter state.

Table 3.7: Provision of personal care at time of joining pilot

Source of care	Number of participants (n=24)
Household members only	9
Household member and other relative	1
HCS only - own home	1
- group home	1
HCS and household members	5
District nursing and household	2
Private nurse and household	1
Nursing Home staff only	3
Nursing Home staff & HCS (weekends)	1

3.6 Personal income

Personal income, rather than household income was considered to be the more appropriate descriptor for this group of people for two reasons:-

i) only five people, at the time of applying to join the project, would have been required to provide information about the income of another person if applying for existing Social Security pensions or benefits (four dejure and one defacto spouse). One married participant is blind, hence not subject to means testing.

ii) changes in relationships during the course of the project resulted in two dejure relationships ending, one dejure and one defacto commencing. The extent of change in household income over even this brief period of time would thus render the information at a given point, misleading.

Table 3.8: Personal income from all sources as at December 1984: $ per week

Total income/week $	Number of participants (n=24)
< 150	14
151 - 300	4
301 - 400	2
401 - 500	2
> 500	2

Three of six incomes over $300 per week did not continue for the duration of the project due to unemployment (retrenchment, contract terminating, resignation).

A very similar distribution of incomes was found in a sample of personal care users of the Home Care Service of NSW (see Section 8).

Three participants have received payments from insurance companies on account of their injuries and two have cases pending (a workers compensation claim relating to an accident in 1982 and a claim involving alleged negligence of a government department relating to an accident in 1979).

The three settlements received were $70,000 in 1982 (Public Risk Policy), $275,000 in 1977 (Third Party, motor vehicle accident) and $500,000 in 1980 (Third Party, motor vehicle accident). After purchasing homes and cars and suffering the effects of inflation, two of these people now receive invalid pensions (one full, one part). Income generated by capital had been used previously to purchase personal care by one person.

The major source of income for each participant is shown in Table 3.9 together with the numbers of participants in each major category of income, receiving additional income from other sources.

Three participants became invalid pensioners during the pilot, one moved from part to full pension and two moved from invalid pension to wages.

Table 3.9: Sources of income as at January 1984

Major source of income	Number of participants (n=24)	Number of participants with secondary sources of income
DSS Pensions/Benefits/Allowances:		
Sheltered Employment Allowance	4	0
Rehabilitation Allowance	2	0
Invalid Pension - Full	6	1 (wage)*
- Part	2	2 (wage, investment)
Sickness Benefit	1	0
TOTAL DSS	15	3
Foreign Government Accident Pension	1	0
Superannuation Pension	1	1 (investment)
Wages	6	1 (investment)
Investment	1	1 (wages)

* Blind Pensioner

3.7 Employment

Employed participants were in open or sheltered employment, the distinction being not necessarily the tasks performed or the employing body but rather the basis and method of remuneration. Similarly those engaged in voluntary work, did so for organisations of the disabled or for other community or business enterprises.

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Table 3.10: Basis of employment/study

Remuneration	Organisation of the disabled	Other govt, private	Educational institution (students)	Unemployed
Sheltered employment allowance	4	*	*	*
Rehabilitation allowance	*	*	2	*
Wages/contract	4	4	*	*
Nil	2	4	*	4
TOTAL	10	8	2	4

Half of the voluntary workers do so part time, as does one person working for wages/contract. Both students are full time. One unemployed person is responsible for a young child.

Table 3.11: Nature of work/study

Nature of work	Number of participants (n=20)
Unskilled/factory	1
Clerical/office	12
Professional	7

3.8 Education

Table 3.12: Highest level of education attained

Highest level	Number of participants (n=24)
No Certificate	4
School Certificate	9
Higher School Certificate	4
Technical College Certificate	2
Diploma/Degree	5

One young participant completed his Higher School Certificate requirements before the pilot finished; tertiary studies were completed by another.

3.9 Health

The presence of health problems, additional to the basic disabling condition is very much related to the nature of that condition. More than three quarters (77%) of participants with spinal injuries reported chronic health problems, urinary tract infections being the most frequently mentioned problem. Other problems commonly associated with spinal injury, autonomic dysreflexia, kidney problems, hypertension and decubitus ulcers were limited to a few participants only, (3, 4, 4 and 3 respectively).

Only one third of those with disabling conditions other than spinal injury considered they had any health problems (two asthma/bronchitis, two hypertension).

Overall three participants accounted for the majority of the health problems listed.

3.10 Transport

None of the participants has access to normal public transport due to design inadequacies of vehicles and boarding structures. Eleven drive suitably modified cars, requiring assistance to transfer in and out. Expensive features such as air conditioning, power steering and large size are considered essential for both safety and convenience. Six people own vehicles for which they require a driver (two are modified vans which can accommodate electric wheelchairs) and three are often passengers in a parent's car. Four use modified taxi buses almost exclusively, giving them the advantage of having their electric wheelchairs wherever they go, a critical factor for independence. Taxi buses are often used even by those who drive, to avoid the necessity of assistance with transferring but cost (even at the government subsidised half-rate) may be prohibitive for some.

4

ASSESSMENT

4.1 Introduction and Approaches to Assessment

Assessment was required to determine the eligibility of applicants (they had to be severely disabled and at their maximum level of independent functioning), to describe the attendant care needs of those selected to participate, to monitor attendant care need and independent living achievements during the pilot and to examine the factors determining attendant time required.

Specifically , the assessment issues addressed were:-

. determination that participants were at "maximum level of independent functioning" i.e. the function of attendant care was seen as a means to meet the residual short falls in independent living, rather than as having a teaching or training function.

. assessment of attendant care needs of participants

. degree to which independent living was enhanced by attendant care

. monitoring of changes in attendant care needs and independent living

. relationship between "functional ability" and attendant care needs

. other factors affecting attendant time, for example the use of equipment

A review of studies which aimed to assess abilities was carried out and the current status of the local developments in this area was considered in order to put the work of this component of the research into a relevant context.

4.1.1 Measurement of Impairment and/or Resultant Disability

Measurement of impairment is usually seen in a medical or clinical context where the aim is to quantify in some way the loss or 'abnormality' of anatomical structure or bodily function. The relationship between such a measure and performance of everyday tasks of living is not necessarily made explicit.

The acceptance that there is not in fact a one to one relationship between impairment and disability led to the development of the concept of 'functional status' as a means of defining disability in 'practical' terms. The maximising of abilities in personal, work and social tasks important to the individual is of course the core of rehabilitation philosophy and it is in this field of study that the attempts to develop measures of functional ability have occurred (Smith, 1984). Much of this work continues to be in a clinical setting, often with the aim to take a baseline measurement of the individual's abilities at a given point following injury or illness and to monitor progress during the administering of , or participation in some treatment regime or rehabilitation programme (Harvey and Jellinek, 1983). A review of relevant literature indicates that, while there is general agreement as to the key factors that should be rated to assess functional ability, there is a lack of consensus as to how measurements should be made. Keith (1984), acknowledges this and outlines the limitations that many measurement scales suffer in terms of well-researched characteristics. Most are developed according to the particular setting and do not necessarily recognise the importance of broader conceptual issues, criteria used for judgement and properties such as standardisation, reliability and validity.

Many attempts have been made to improve the credibility of functional scales with, as yet, no definitive results. Kaufert (1983) identifies four major measurement problems in ensuring the validity of functional assessments and attempts to evaluate the impact of these; use of equipment and assistance, situational and motivational variation, rater perspective and role expectations of the individual. Kerner (1981) also attempts to evaluate inter-rater reliability and criterion validity by comparing the use of gross or overall scores and ratings of the individual components of a task. Jette, (1980) and Susset, Vobecky and Black (1979) both use self report assessment methods to look at characteristics of a functional status index and a disability outcome measure respectively and find this approach successful for their groups.

4.1.2 Determination of Independence

The realisation that impairment, disability and handicap are part of a complex relationship influenced by physical, psychological and social factors does not appear, however, to have lessened the complexity of issues in relating an assessment of function to a 'real life' needs situation. Often the broad scales which attempt to rate people by scores fail to separate the individual as a biological entity from the individual as a member of a household (Kessler, 1970). It is this point that emerges strongly in looking at the relationship between functional status and attendant time required in this study pilot project.

Independence has traditionally been viewed in terms of the common activities of daily living (ADL) that form the basis of functional abilities. A variety of such measurements has been described in the literature (Selman and Barnitt, 1983, Kane and Kane, 1981) so will not be discussed in detail here. Most comprise key elements of self care and mobility with varied methods of rating (letters, numbers, observation, self report) and vast differences in ease of completion. Donaldson, Wagner and Gresham (1980) attempt to combine the attributes of several scales into one form, comprising fourteen sections which can be rated in a time varying from 15 to 60 minutes, depending on whether the person is already known to the rater. This 'assessment' time will of course be a factor for consideration in the administering of any service or scheme.

The social philosophy which includes the concept of attendant care goes further towards qualifying what independence might really mean, rather than just being an isolated measure of what a person can and cannot do. Keith (1984) suggests that in fact the appropriate use of assistance could be shown to enhance independence but this will not necessarily be reflected in a score of functional status.

4.1.3 Who Should be the Assessor

With the seemingly divergent developments of a move towards a more critical approach to assessment of function by rehabilitation practitioners and a social movement maintaining the rights of the individual in decision making, some dispute emerges concerning who should influence the decision as to what services are provided for an individual. Discussion of this issue appears not only in the writings of the Independent Living Movement but also emerges in studies looking at the planning of community services. Seidl et al (1983), in a description of a project that set out to demonstrate a working model of home-delivered services to elderly and adult disabled people, question the reliability and validity of professional judgements on which assessments of clients at risk for admission to nursing homes was dependent.

In a study of institutional versus community care, Sager (1983) specifically addresses the question of professional, 'patient' and family views of home care needs and also looks at agreement between various professionals when prescribing care requirements.

The application process for services under the In Home Supportive Services program in California involves the completion of a needs assessment form by a social worker in conjunction with the applicant. A rating is given to the main areas of personal care function, followed by a noting of services requested by that person which cannot be performed by others within the household or cannot be obtained from other sources.

Many of the American consumer-based centers for independent living incorporate guidelines for defining attendant care needs to assist their clients to apply for services and subsequently with management and training of attendants.

With this background, the procedure adopted in this study was to:

- select a measure of functional status
- determine attendant care needs and allocate time accordingly
- examine the relationship between these two factors

4.2 Selection of Measures

4.2.1 Available Measures

When surveying commonly used and/or well researched measures of functional ability which are currently available in the Australian context it was found that they similarly reflect attempts to come to terms with the complexity of issues described above. No single format or direction for assessment measures has been identified or developed. A person with disabilities might well be faced with 'assessments' in a variety of areas such as:

- nursing home admission/extensive care benefits
- hostel admission/personal care subsidy
- pension/benefit application (Invalid Pension, Mobility Allowance and subsidised taxis)
- eligibility for community services (home help, delivered meals, community nursing and personal care assistance)
- medico-legal claims for compensation

A variety of personnel may be involved in these processes and the individual may or may not take an active part or even know that assessment is taking place. Most of these assessments are currently considered to require certification by a medical practitioner.

Many rehabilitation groups develop their own procedures to suit a particular client population to measure what they think is important. Some attempts, however, are being made in some medical and rehabilitation settings to profile an individual's abilities and to design a treatment programme accordingly.

A typical assessment of this type will be ratings, sometimes in minute detail and by various team members, of several aspects of daily living. While this might give a picture of a person's function at that point of time and in that setting, it may not relate to a real situation. In the broader sense, such assessments are not necessarily seen as an integral part of official records so there is little opportunity for ongoing review or development. They are often too detailed and may rate overlapping skills with limited efforts to isolate key skills that might give just as meaningful a picture when describing overall functioning.

4.2.2 Selection of Measures

As the assessment of attendant care requirements was not considered to have the same focus as these clinical type measurements, consideration was given to any work being done with a similar population ie. the working age group who are potentially, if not already, consumers of long term community supports and who have very different needs than the elderly.

Disability Profile

Colville's (1983, 1984) Disability Profile was selected for use in this project. It was originally compiled for use with clients of the Multiple Sclerosis Society of Victoria. A summary of the profile is included in Appendix E. This comprehensive assessment form sets out to give an overview of an individual's abilities and difficulties related to physical and psychological functions that influence living arrangements, care required and intervention that may be necessary. It is used to indicate changes over a period of time and, although rated in what might still be regarded as a clinical setting, recognises crucial aspects such as social and financial issues, behaviour towards others and psychological factors that ultimately influence choice of living situation.

There are two aspects of this profile that were considered particularly worthwhile for use in this study:

i) Barthel Index (Mahoney and Barthel, 1965) - a score given as a total of ratings in personal care tasks and mobility (items 16-25 and 27-32 respectively). A score of 100 (maximum possible) describes a person who is able to carry out all basic personal care tasks independently. It does not necessarily mean that that person can manage other household tasks. A score less than this therefore signifies the need for assistance with personal care. The Index was adapted by Granger (Sherwood, Morris, Mor and Gutkin, 1977) into a series of ordinal scales which comprise the Barthel Self Care Rating. This scale sets out to define in more detail the steps of a functional activity and the degree of assistance required. The Barthel Scores and Barthel Self-Care Ratings are recognised as well established and tried scales that are sensitive to change and are weighted according to relative significance of various tasks to independent living. (Mahoney & Barthel 1965, Kane & Kane 1981).

ii) "Nursing Care Load" - a measure (in hours) of the physical workload that is required from other people to assist the individual, calculated from the ratings given to self-care, mobility and accessibility of environment items. A weighting of items is given which computes a daily time value. Caring load in relation to physical needs is calculated in tenths of an hour for each level of deficit in ADL function. Colville (1983, 1984) describes some success in using this format in the population previously described.

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All items of the profile are rated on four levels:

- Yes I can on my own
- No I can't
- If I can, do I do it easily or with difficulty (A or B)
- If I can't, do I need minor or major assistance (C or D)

Colville (1983,1984) claims this will produce a ranking with disparity of not greater than 5% between different observers.

For the purpose of this study, the items relating to these two scores were the main focus; other items considered as requiring an actual physical assessment or which related particularly to the original target group (clients of Multiple Sclerosis Society) were not rated specifically in the process of relating functional status to attendant care requirements. The score sheet used is included in Appendix B.

To the extent that the pilot was required to compare attendant care costs with institutional costs for this group of people it was necessary to ascertain their eligiblity for institutional care. The level of severity required for participation in the pilot (not less than 2 hours and not more than 4 hours per day) should also meet the eligibility requirements for occupying a bed attracting the Nursing Home Subsidy. To test this, applications for nursing home entry (NH5) were completed for each participant and submitted to a Commonwealth Medical Officer in the Nursing Home Benefits Branch of the Department of Community Services.

Participants' own assessments of the attendant time required, based on their knowledge of the time taken by their current volunteer or paid carers, were used to determine hours required and examined in relation to Colville Profiles. As has been discussed, this element can be acknowledged as a major component for making a realistic judgement about the amount and type of assistance required. Existing attendant care schemes use a needs assessment compiled by the person making the application for assistance in conjunction with the administrative procedure, as described above.

4.3 Determination of Attendant Care Requirements

During the initial application process, it had been established that those selected met the basic eligibility criteria, specifically those relating to level of independent functioning and requiring between two and four hours assistance per day. Eighteen of the twenty four selected had been clients of the Commonwealth Rehabilitation Service (CRS) at some time prior to joining the pilot. All 13 with spinal injuries had attended rehabilitation programs at the Mt Wilga or QEII centres for a period of at least six months (one as long as fourteen years ago and two as recently as the previous year). Four others had undertaken short term rehabilitation programs (one of three months duration) on a regional basis from a centre. Another had received assistance from a Regional Unit of CRS.

The NSW Society for Crippled Children, the Spastic Centre of NSW and the Multiple Sclerosis Society had been involved in habilitating or rehabilitating four, four and two participants respectively.

The assessment of maximum level of functioning was a decision made by the occupational therapist and participant based on a combination of factors:

(i) the majority had had opportunities for enhancing physical abilities as has been described
(ii) certain physical disabilities do have specific accepted functional aspects, for example the various levels of spinal cord injury determine specific disabilities and abilities
(iii) judgement of reasonable expectations e.g. if it is possible to dress or cook without assistance but this involves considerable time and energy and/or an element of risk and frustration, then it should be an individual's choice as to what priority these abilities assume within a lifestyle.

For each participant therefore, attendant care was considered to be meeting the shortfalls in independent living.

A follow-up visit was made to the home of each participant, at times to suit the individual. In two instances, the presence of a family member was required to assist with communication.

Information was recorded concerning

- general physical function
- social situation/supports
- employment
- general health

and is reported in Section 3.

The equipment being used and the building modifications which had been done on account of the person's disability were assessed to determine whether additional or different equipment or building modifications would be necessary to minimise the attendant time required.

All participants used some form of 'equipment', much of which could be seen to be reducing either the amount or type of assistance required for example:

- powered wheelchairs
- lifting hoists
- shower/commode chairs

This equipment is relatively expensive and beyond many participants' private means to pay. Table 4.1 shows how the purchase of these items had been financed in the past. Following this assessment of equipment five participants requested information about, or assistance with the purchase of equipment.

The use or absence of a piece of equipment can be seen as having a direct influence on both paid and unpaid assistance. The example of assistance with transfers illustrates this most clearly.

Of the nineteen participants who required complete assistance for some or all of their transfers, nine had a mechanical lifting hoist for use when required (frequency of actual use varied). Five people reported choosing the assistance of two people for some transfers rather than using the hoist. The second assistant was a household member. In one of these cases a change in household circumstances meant the second assistant was no longer available at weekends so an increase in paid time was necessary until the various options regarding hoists could be considered and financial arrangements made for the purchase of a suitable hoist. This temporary allocation of extra hours was intended to meet an emergency only but the period for which it was required was dependent on the availability of finance and equipment.

For another participant his first attendant employed did not find it necessary to use a ceiling hoist (installed previously when his mother was providing his personal care) and this did not result in extra time. Both attendant and participant were satisfied with this lifting technique at that time but a later attendant did not have the necessary physical strength to lift alone so once again the hoist was required. Again, no additional time was required to meet the new arrangements.

During the course of the project, ten participants required modifications to their homes to enhance independence and therefore decrease attendant time, or to prevent an increase when moving into unmodified accommodation. Of these, four were financed and arranged by the Housing Commission, two were paid for by the CRS (for two people undertaking an independent living program) and four were paid for by the disabled person or his family. The occupational therapist liaised with the organisations concerned and advised on design aspects when relevant.

Table 4.1 How the most recent replacement of each item was financed by participants

Item	Self	YACS/ PADP	CRS	Insurance Co.	Other
Shower/ Commode Chair	7	8	4	1	
Manual Wheelchair	8	9	7	1	3
Electric Wheelchair		8	2		
Lifting Hoist		5	4	1	
Electric Bed		6	2		
Ripple Mattress			2		
Car Conversion	7	1	1		

4.3.1 Completion of Ability Profile

Using discussion and self-report, the relevant items in the profile were rated, giving a status score in self-care and mobility.

All participants required some degree of assistance in all personal care tasks, rating the need for the presence of another person for some time in the preparation of or during a task. Tables 4.2, 4.3, 4.4 present the ratings of assistance required with personal care tasks, transfers and wheelchair mobility.

Table 4.2: Assistance with personal tasks (N = 24)

Rating of Assistance Required	Assist at Toilet	Dressing		Grooming	Bath/ Shower	Drink from cup	Eat from plate
		Upper Body	Lower Body				
Prior Preparation		1		12		17	18
Presence of Helper	9	7	2	7	8	4	3
Complete Assistance	15	16	22	5	16	3	3

Table 4.3: Assistance with Transfers (N = 24)

Rating of Assistance Required	Bed/Chair to Wheelchair	Toilet to Wheelchair	Bath/Shower Wheelchair
Indep/ Slideboard	1		
Presence of Helper (min.lifting)	15	5	5
Complete Assistance (Lifted)	8	19	19

Table 4.4: Wheelchair mobility (N = 24)

Rating of Assistance Required	Number of Participants
Able to walk short distance with helper and/or crutches (also use chair)	2**
Able to propel manual wheelchair 100m, slight grades, step, round corners	4
Requires powered chair, or able to propel more than 20m, less than 100m, or slow*	19
Requires assistance to propel wheelchair	1

*Number of participants using powered wheelchair most of the time = 11

**These two also counted as wheelchair users

Two scores computed from the Profile were subsequently used in the comparison between independent functioning and time requirements.

These are:
- Barthel Index
- Caring Load

A low score reflects a high degree of disability and therefore major assistance required, as discussed previously.

Of those participants with quadriplegia, all except one were considered to have "complete" lesions with the majority being described as injured at the C5,6 level i.e having some arm movements and limited hand function. Two with lower scores were injured at the C4,5 level and thus had less useful arm function.

Table 4.5: Barthel Score and Caring Load (calculated from Colville Profile) related to Disabling Condition (N = 24)

Barthel Score	"Caring Load" hours/week	Disabling Condition
10	50	Cerebral Palsy
15	50	Cerebral Palsy
20	46	Quadriplegia (4/5 lesion)
25	43	Cerebral Palsy
25	43	Muscular Atrophy
25	43	Muscular Dystrophy
26	46	Quadriplegia (4/5 lesion)
27	42	Muscular Dystrophy
32	34	Quadriplegia (5/6 lesion)
32	34	"
32	34	"
35	32	"
35	36	"
35	43	"
36	35	"
37	31	"
37	34	"
42	27	"
47	35	Multiple Sclerosis
51	25	Multiple Sclerosis
51	32	Cerebral Palsy
52	28	Quadriplegia (incomplete lesion)
56	21	Muscular Dystrophy
58	20	Post-Poliomyelitis

Every participant was certified as eligible to occupy a bed attracting the Nursing Home Subsidy when NH5 applications were assessed by a Commonwealth Medical Officer of the Nursing Home Benefits Branch of the Department of Community Services.

4.3.2 Assessment of Attendant Time based on daily routines

The basis for the initial allocation of time was the daily routine of the individual involving the key personal care tasks for which assistance had previously been obtained from family, friends or in some instances paid workers and in the case of those living in institutions, paid staff. These tasks have been accepted as the major focus of attendant care:

. assistance with eating
. showering
. dressing
. bowel/urinary care
. grooming
. health/hygiene
. skin care
. transfers, posture, turning, pressure relief

Much of this could be considered "ordinary, everyday" work taken for granted by most, and therefore it should be possible to allocate a standard time accordingly. However certain aspects of these tasks may take varying amounts of time for different people and indeed by the same person on different occasions. The very individual characteristics of each person should be taken into account when assessing time allocations. These variations partly explain the range of time requirements shown by different people who could be said to rate similarly on a physical scale. For example,

. Assistance with meals - this could involve some preparation where no one was available within a household, or the actual physical assistance in eating the food. A minimum requirement would be help in serving or cutting up while a maximum requirement would be continuous assistance during the meal if a person has swallowing difficulties.

. dressing - for some people extra time may be involved in the fitting of such "extras" as a brace, corset or caliper.

. urinary care - consideration was given for time involved in preparation and fitting of collecting devices, (uredome, leg bag) assistance during the day in emptying leg bag.

. bowel care - for some participants the time requirements were governed by the need for assistance in maintaining a set pattern, for example, using enemas.

65

. skin care- for those with impaired sensation this might involve following instructions from the participant in checking for "red" areas or a careful approach in carrying out some tasks - for example transfers, drying skin after washing to protect against damage.

Insertion of catheters or treatment of a skin problem were not considered generally to be part of the role of the helper in personal care assistance. Some participants therefore had contact with other agencies for assistance required in such areas.

. posture, pressure relief - apart from routine transfer, some participants required assistance in maintaining or changing position during the night or day. This might be for pressure relief in the case of someone with impaired sensation or for comfort or pain relief in the case of someone with sensation but unable to voluntarily change position of limbs. This is one aspect of intermittent, sometimes unpredictable assistance that complicates the allocation of regular "block" amounts of time.

A further factor used to refine time allocation was the consideration of what might be a reasonable length of time for which payment would have to be made. For duties requiring perhaps only fifteen minutes (e.g. a transfer into bed) it was necessary to allocate a minimum of one hour to make it worth an attendant's while to come. Efficient use of the 'extra' time is discussed later. Participants could however negotiate varying minimum work shifts with individual attendants depending largely on the travel distances involved.

Discussion of overall weekly requirements also included the assistance that would be provided by other household members, friends or workmates. This voluntary source provided much of the intermittent often unpredictable assistance required usually amounting to much less than an hour on any one occasion.

Some participants also chose not to use an attendant to meet all personal care needs. In some instances this was taken into account in the initial estimation of hours required whereas for others a decision was made after commencement. The resulting 'excess' hours were then used for other household tasks i.e. it was clearly a tradeoff situation in which personal care tasks were swapped for household tasks by the household member concerned. This was particularly useful in cases where the performance of at least some of the personal care suited a particular relationship.

4.3.3 Allocated Hours

The hours allocated on the basis of proposed routines presented during the home visit interview are given in Table 4.6, with participants classified by disabling conditions.

Table 4.6: Allocation of hours

	Number of participants - disability group				
Hours/Week Allocated	Quadriplegia	Multiple Sclerosis	Cerebral Palsy	Post-Polio-Myelitis	Musuclar Dyst/atrophy
14	*	*	1	1	1
15.5	*	1	*	*	*
16	1	*	1	*	*
17.5	2	*	*	*	*
18	1	*	1	*	1
19.5	3	*	*	*	*
20.5	1	*	*	*	*
21	3	*	1	*	*
22	1	*	*	*	*
23	*	*	*	*	1
24	*	1	*	*	*
28	1	*	*	*	1

The routines proposed by all participants included a core period of time morning and evening as for most, their assistance required during the day was minimal, or was available through other sources, for example at work. These routines were in some instances based on already established patterns, while for many they represented an anticipated change being made possible by the provision of assistance from outside the household. Some changed these routines during the course of the study as they adapted their attendant time to their lifestyles. An allocation of time should not therefore be seen as a static amount which will necessarily be used in a set way; it will change as the individual does.

Examples of Proposed Routines

1. 14-hour allocation

This allocation represented one hour each morning and evening to assist in the preparation for going to work and going to bed at night. Complete assistance was required in all tasks, but no heavy lifting or special requirements were necessary for bowel and urinary care. Extra assistance during the day with personal care (including meals) was minimal and was available at work or from another household member if at home during the day. Assistance, however was required in other areas (all household tasks, turning in bed during the night, extra transfers), involving a considerable time commitment for a household member. Attendant hours would be increased were such household assistance to become unavailable for any reason.

2. 21-hour allocation

The routine selected by this participant could be considered fairly typical of that established by many people with a spinal cord injury requiring a set bowel care regime:

3 mornings/week	3 hours
4 mornings/week	1 hour
7 evenings	1 hour

The variation in the major hourly requirement is due to the lack of reliability in predicting the time taken for the morning routine (in some cases evening). In this instance the reported variation was between 2 and 3 hours on some days, therefore the allocation had to be for the greater amount. Any "unused" hours were then available for use for other household tasks such that the disabled person was able to provide his "share" of domestic duties.

3. 19.5-hour allocation

4 mornings/week	2 hours
3 mornings	1.5 hours
7 evenings	1 hour

A different routine for a person with, theoretically, the same needs as the person in example 2, but a more predictable bowel care time, managed with a slightly smaller allocation of time. A greater proportion of the domestic duties, in this case were performed by a household member.

4. 28-hour allocation

This participant had developed a routine to allow himself a fairly standard time of assistance each day and incorporated the necessary tasks into the time that was available on different days, for example, when the bowel care routine involved "waiting" time for the attendant, other tasks such as preparation of clothes or assisting in food preparation would be assigned. Assistance needed during the day was minimal if adequate planning had ensured that food and other requirements had been put in accessable places by the attendant during the morning session.

Table 4.7 Allocated hours in relation to routines

Participant	Total Hours	Morning	Evening	Extra	
	Per Week	Hours X Days	Hours X Days	Hours	Purpose
1	14	1 x 7	1 x 7		
2	14	1 x 7	1 x 7		
3	14	1 x 7	1 x 7		
4	15.5	2 x 7		1.5	Exercises
5	16	1.5 x 4; 1 x 3	1 x 7		
6	16	1 x 7	1 x 7	2	Toiletting
7	17.5	1 x 7	1.5 x 7		
8	17.5	1.5 x 5	1 x 7		
9	18	2 x 3; 1 x 2; 1.5 x 2	1 x 7		
10	18	1 x 7	1 x 7	4	Grooming
11	18	1 x 5; 2 x 2	1 x 7	2	Grooming
12	19.5	1.5 x 4; 1 x 3	1.5 x 7		
13	19.5	2.5 x 3;1.5 x 2;1 x 2	1 x 7		
14	19.5	2 x 4; 1.5 x 3	1 x 7		
15	20.5	1.5 x 5; 3 x 2	1 x 7		
16	21	2 x 7	1 x 7		
17	21	2 x 7	1 x 7		
18	21	1 x 7	2 x 7		
19	21	3 x 3; 1 x 4	1 x 7		
20	22	3 x 3; 1.5 x 4	1 x 7		
21	23	1 x 5; 2 x 2	2 x 5; 2 x 2		
22	24	2.5 x 5; 1 x 2	1.5 x 5; 1x 2		
23	28	2.5 x 7	1.5 x 7		
24	28	2 x 7	2 x 7		

4.4 Re-assessment Procedure

Changes in the formal allocation of hours could occur following the six-monthly routine visits by the occupational therapist or following a request from a participant in response to a change in circumstances, either short term or permanent.

Due to the importance of collecting accurate ideas and opinions for the research issues, it was agreed that no decrease in hours would occur on the basis of information given to the research team about the use of allocated hours or allowance. Therefore a mechanism for decreasing hours in cases where less than the total allocation was being used, was not instituted. The actual use of allocated hours is described in Section 5. For this group, as discussed previously, disabilities were such that the need to assess for marked improvements in physical function was not considered appropriate.

Factors being considered in the changes to allocation were:

- change in functional status
- change in social situation
- satisfaction with using assistance provided by other household members
- satisfaction/dissatisfaction with hours or routine

4.4.1 Temporary Increases

Changes for one-off occasions or for up to two weeks could be made by contacting either the occupational therapist or co-ordinator. Approval by phone could be given if a visit was considered unnecessary or if the need was immediate. Where such a request might lead to a longer or permanent increase a re-assessment visit was required by the occupational therapist. Four such changes were requested for reasons as outlined in Table 4.8. There were no requests from the coordinator for re-assessment for the two cases where there appeared to be a rather regular use of extra time.

4.4.2 Permanent Changes to Allocated Hours

Increased allocations were approved for eight participants, three of whom required more than one adjustment (see Table 4.8). In one instance the increase was at the direct suggestion of the occupational therapist following discussion during a routine visit, while the remaining increases were in response to requests from participants themselves. The size of each increase was subject to discussion.

An increase for one participant, made necessary by a change in household composition, was arranged by the coordinator without reference to the occupational therapist. This increase was in conjunction with hours to be provided by the local Home Care Service Branch for cooking.

Table 4.8: Summary of Increases to Allocated Hours

Participant Group	Time after commence- (months)	Increase in allocation (hrs/wk)	Temporary allocation (hours)	Reason
Allow. 1	8	2		Reported restrictions in going out independently, increase allowed for transfers, preparation to go out, assistance with personal shopping.
Service	6	2		Often going to bed when attendant assisted with transfers after work rather than split evening hours or rely on mother. Increase given to cover this and preparation for going out in evening.
	6		2 (occasional)	Assistance in attending out-patient clinic.
Allow. 1	7	1.5		Change in living situation - flatmate not available to assist with transfers after work.
Allow.2	1	4		Still relying on household member, all morning preparation not being completed in attendant time.
	6	3.5		Move to new living situation, parts of house not accessible, e.g. kitchen. Increase to cover some meal preparation.
	10	1.5		Still relying on another household member, increase to cover cost for grooming, personal washing.
Allow. 1	6		10 (1 week)	To cover cost for nurse to give injections for bladder infection - community nurse not available.
	15		4.5 (indefinite period)	Change in living situation - another household member not available to assist with transfers - to be reviewed following consideration of/and assistance to pay for lifting hoist.
Allow.2	6	2.5		Move from parents' house to live

Table 4.8: Summary of Increases to Allocated Hours (Continued)

Participant Group	Time after commencement (months)	Increase in allocation (Hrs/Week)	Temporary allocation	Reason
				with friend. Increase for assistance with transfers during the day, light meal preparation, personal washing.
Service	4	1		To cover assistance given by household member who had moved- evening transfers.
	20	2.5		Further change in living situation - assistance with meal preparation, personal washing.
Service			2/week (occasional)	To assist in going out- personal shopping.
Allow.2	3 8	12 6		Combination of decrease in abilities and change in social situation.
Allow. 2	10		4 (1 week)	To cover holiday visiting family where facilities not as accessible, travel time, change in routine.

4.4.3 Decrease in Functional Status

For only one participant was there a change made to allocated hours as a result of decreased functional ability associated with the expected progression of her degenerative disease. Two requests for increases were approved for this person bringing her total allocation to 42 hours per week. The decision to exceed the project's maximum hours per week was in keeping with the National Steering Committee's decision that there would be guaranteed continued assistance to participants for the duration of the pilot even when increases took the total beyond the initial maximum.

The decrease in functional ability itself, however, was not the key factor in determining the hours of assistance required by this person. Theoretically it was possible to justify the need for six hours personal care assistance per day as follows:

2 hours each morning (transfers, bowel and urinary care, showering, dressing and breakfast)
1.5 hours at lunchtime (presence of another required during meal, assistance to toilet)
1.5 hours each evening (as for lunchtime)
1 hour at night (preparation for and transfer to bed)

As functional ability decreased the key factor determining hours required was the need for the presence of another person in the house at all times. A secretary, employed as part of some work being undertaken by this participant, spouse and parents initially met much of the need for intermittent assistance and provided the security of just being there. When the secretary was no longer employed an increase in hours from the pilot met the shortfall. Some assistance was also paid for privately and the participants's mother visited regularly. A change in the husband's work committments (hours somewhat unpredictable) and a deterioration in the mother's health increased yet again the level of paid assistance required. The possibility of nursing home accommodation was considered and rejected because the participant wished to continue in her current lifestyle living with her husband.

In the following months there was considerable weekly variation in the attendant time required depending on the hours her husband was away at work i.e. paid attendant hours were approximately equal to husband's work hours. If the work hours exceeded the average hours provided by the pilot, extra hours of care were paid for privately.

4.5 The Relationship between "Functional Status" and Attendant Time Required

The hours allocated on the basis of self reported need, taking into account the anticipated level of use of voluntary hours, will now be examined in relation to functional level as measured by the Colville Profile, which was re-administered during each of the two re-assessment visits. The second time as with the first, was based on discussion and self report but the third was completed by the participants alone.

Table 4.9: Summary of Assessment Scores

Initial Assessment			Reassessments						Total Personal Care (incl. vol. hours)
			First			Second			
Attend Hours	Barthel	Caring Load	Attend Hours	Barthel	Caring Load	Attend Hours	Barthel	Caring Load	
14	25	43	14	25	43	14	32	39	23
14	27	42	14	32	41	*	*	*	17.5
14	58	20	16.5	46	28	16.5	60	19	18.5
15.5	51	25	15.5	51	25	15.5	54	21	17.5
16	15	50	16	15	50	16	30	47	25.5
16	52	28	16	52	28	16	66	24	17
17.5	26	46	19.5	22	48	19.5	32	38	24
17.5	42	27	17.5	42	27	17.5	39	25	20.5
18	20	46	18	20	46	18	17	55	21.5
18	25	43	25	25	43	27	32	34	29
18	51	32	18	46	36	18	43	31	21
19.5	32	34	20.5	32	34	24	33	37	25.5
19.5	32	34	19.5	32	34	*	*	*	*
19.5	35	43	21	35	43	21	39	38	23
20.5	37	34	20.5	37	34	25	27	38	28
21	10	50	21	10	50	21	10	44	27
21	32	34	21	32	34	21	21	44	24
21	35	36	21	35	39	21	37	34	24
21	36	35	23	34	36	23	39	36	25
22	35	32	22	35	32	22	52	20	25
23	25	43	23	25	43	23	30	39	28
24	47	35	36	32	39	42	23	48	52
28	37	31	28	37	31	28	50	22	29
28	56	21	28	47	27	28	49	28	28.5

* No data available

The Barthel scores and Caring Loads rated by the occupational therapist and participants and the allocation of attendant time are shown in Table 4.9. The correlation between the first and second ratings (.9) signifies the reliability of use over a six month period. The correlation (r=.8) between the second and third ratings shows a good level of agreement between the occupational therapist's judgement and the participants' ratings of their own abilities, suggesting the suitability of this instrument for inclusion in an application form to be completed by applicants themselves. The low correlation between allocated hours and (i) the Barthel (r = .14) and (ii) Caring Load (r = -0.2) is hardly surprising in light of the previous discussion of how the allocated hours were determined.

The Barthel Score gives an overall estimate of the level of disability and as such may provide useful confirmation of a person's eligibility to receive benefits from a scheme specifically restricted to people with severe disabilities. As has been discussed, a rating of 100 signifies complete independence in personal care and mobility. It is possible to obtain a lower score and still be independent in personal care but it is not feasible to set a point below 100 as the upper limit for inclusion (e.g. a person with paraplegia, completely independent in all aspects of ordinary daily living, may rate only 85 due to 'inability to walk and climb stairs' only partly compensated for by good wheelchair mobility score but would score 0 for Caring Load unless in a very inaccessible environment or suffering with skin problems).

The Barthel does not necessarily, however, take into account other factors, obviously influencing the actual attendant time required i.e. social situation, individual preferences in regard to care requirements and individual lifestyle priorities.

For example:

Two participants, with the lowest scores on functional ability, rating themselves as requiring a high degree of assistance in all areas of personal care and mobility, did not request attendant time to meet all these needs. Both have assistance available during the day at work and both live with families who still provide a significant amount of assistance at times other than the major "care" periods. Of course, requirements would be different if these social situations changed.

Two other participants, both sharing houses with friends who also have disabilities, and who thus cannot assist with personal care have ratings which can be considered to reflect both their needs and what they typically use in attendant time. Both have similar ratings (50, 49) of abilities and use 28 hours/week. Both can manage without assistance during the day because their home environments and facilities are accessible.

The two participants scoring highest in the group on functional abilities on their own ratings, receive core amounts only for personal care tasks (2 - 2.5 hours/day). Both have a practical degree of independence during the day, i.e. can spend major periods of time alone, drive to work and require only minimal extra assistance intermittently. (e.g. for transfers), providing the environment is accessible. While both provide a major component of household management, some assistance is required in these tasks (shopping, housework, washing).

4.5.2 Estimating Total Assistance Required

Participants were asked to estimate personal care assistance obtained from people other than paid attendants in a typical week e.g. from other household members, friends or people at work, in an attempt to estimate total requirements. This did not include any assistance provided as part of a trade-off arrangement. Participants were asked to count only those tasks included in items 1 to 18 of the Colville Profile. While it is easy to define the tasks, it is no easy matter to separate the time taken into discrete amounts, nor are these the only personal care tasks. Assistance in obtaining a drink may involve another person making all preparations and putting the cup within reach - does this constitute assistance or part of the ordinary interaction between people ? For this exercise the estimates are based solely on time specifically devoted to providing assistance and are shown in Table 4.9.

The correlation between the estimated total care required and the first two Barthel scores is again low (r = -.2, -.3) but the correlation between the participants' own assessments (third Barthel) and total care required is somewhat higher (r = - .4). In all instances the attendant time allocated was reported to account for the bulk of personal care assistance required, but except for those living alone, did not meet all needs. Unpaid assistance for other tasks was used for meal preparation, laundry, driving, wheelchair maintenance etc, the specific requirements depending on lifestyle and living arrangements. Much of this assistance is provided as part of another person's role within a household and outside assistance is not desired or requested.

4.6 Summary and Conclusions

Eligibility for an attendant care scheme, if such a scheme is to be targeted to the severely disabled, could be determined by,

- functional status score, for example the Barthel Self Care score derived from the Colville Ability Profile, rated by the individual
- eligibility to occupy a bed attracting the Nursing Home subsidy

Each measure would be used to certify eligibility. Ideally, the revisions to the regulations governing nursing homes (types, eligibility, subsidies etc) currently being undertaken, should incorporate assessment procedures specifically for the non-aged severely disabled person such that a common eligibility for either nursing home subsidy or 'attendant care subsidy' could be established.

Attendant Time required is not directly related to functional status but is determined by a complex interaction between functional status, social situation and lifestyle.

The amount of attendant time required may be assessed most simply by itemising the tasks with which assistance is required, dividing such tasks into those to be done by a household member (to the mutual satisfaction of the disabled person and the household members involved) and those to be done by a paid attendant.

If attendant assistance is required with household chores as well as for personal care, it is desirable that they be included in the assessment of attendant time, rather than requiring the person to seek this type of assistance from another agency.

An integration of household chores with personal care, particularly in the many cases where "waiting time" during a bowel routine is involved, makes for a very economical use of paid time.

The time required to perform the tasks nominated for attendant care should be determined in consultation with the individual concerned who would describe when and how the tasks are to be done.

The total time required will not necessarily be a simple addition of separate task times but will reflect the individual's routines and priorities.

A procedure for adjustment to allocation of hours is required to respond to changing needs, both on a temporary and permanent basis.

Assessment does not need to be medically oriented but can best be achieved by means of a co-operative exercise involving the assessor and the person being assessed.

5

THE PROCESS OF ATTENDANT CARE

Research Brief Item B

> "To test various options on how this attendant care might most effectively be provided .... comparison of the advantages of the service and allowance based modes .... critical documentation of the pilot".

This section describes and criticaly analyses how the two models functioned.

Participants were selected and allocated to either the service or an allowance group as described in Section 2.5. Preference for a particular group, expressed at the initial interview, was taken into account. The service group comprised only participants inexperienced in using paid attendants, the allowance group, both those with experience and those without (referred to as Allowance 2 and Allowance 1 respectively).

The delivery of services required in each model was overseen by a Co-ordinator. Over the study period two pilot study co-ordinators were employed by the Home Care Service of NSW, the body contracted to implement the pilot, the first from September 1983 to September 1984, the second from November 1984 to the pilot's conclusion. Differences in approach which materially influenced the operation of the pilot were few in number and are commented upon in the relevant sections. Unless otherwise specified the term 'the co-ordinator' refers to either incumbent of that position. Costing of details of pilot administration are presented in Section 7.

5.1 The Allowance Model

The sixteen people in this model received fortnightly payments. They undertook to:-

- interview, select, train and manage their own attendants, including insurance and payment
- refrain from employing a parent or spouse
- keep accurate records of moneys received and disbursed
- provide all information required by the evaluation team

5.1.1 Allowances

Allowance amounts were based on the hours needed by the participants as assessed by the occupational therapist. The initial hourly rate of $7.51 was the rate paid to Home Care Service Aides at the time. An extra dollar per hour was added to allow for reimbursement of travel expenses to attendants. The basic rate increased in April 1984 and April 1985 to $7.81 and $8.02 respectively, in line with Home Care Service increases.

Allowance cheques were posted fortnightly to recipients' home addresses. To overcome hardship resulting from postal delays, a double allowance was paid in one fortnight soon after commencement, assuring that in future participants would receive allowances in advance of having to make payments. Provision was subsequently made for those participants who wished to have allowances paid directly into bank or building society accounts.

5.1.2 Taxation, Obligations

The Commissioner of Taxation made two rulings in respect of the allowances paid

i) allowances should "be regarded as amounts paid to a taxpayer which, by virtue of section 159P of the Income Tax Assessment Act, are amounts which reduce the taxpayer's gross medical expenditure for concessional rebate calculation purposes. The definition of 'medical expenses' includes payments as remuneration of a person for services rendered by him as an attendant of a person who is blind or permanently confined to a bed or an invalid chair. In these cases the payments (allowances) would not be regarded as income liable to tax." (Taxation Ruling No. IT2052, 1983).

ii) ".... services provided by the attendants would be similar in nature to professional persons attending a person's home to give personal attention, such as physiotherapists, nursing services etc. In the circumstances, it is accepted that tax instalments do not have to be deducted from the payments to the attendants. However it should be understood that the attendants will be required to account for the income in their own personal income tax return". (Correspondence from Acting Assistant Commissioner, Australian Taxation Office, March 1984). This ruling was received after insurance arrangements had been made.

5.1.3 Insurance Requirements

As "employers" of attendants, participants were responsible for arranging adequate Workers' Compensation Insurance cover for their "employees". The pilot reimbursed participants for the cost of this insurance. The co-ordinator facilitated negotiations with one insurance company, GIO, the majority availing themselves of this opportunity while two arranged policies with companies of their own choice and one person made no arrangements. One policy was let lapse after twelve months. The extent of the co-ordinator's responsibility in ensuring that adequate insurance was effected and that the premiums paid were reasonable, was never clear. To the extent that the pilot was meeting the costs, interest in the latter would seem necessary. The premiums paid ranged from $244.60 per annum to $656.73 per annum (mean = $406.89) based on total allowance amounts (including both wages and travel components).

In the light of the taxation department's ruling that allowances are reimbursements, insurance would appear to be solely the participants' responsiblity.

Alternatively, the taxation department's ruling that payments to attendants are to be viewed as 'fees' for services rendered, could be taken to imply that attendants are independent contractors, hence responsible for their own accident cover.

The NSW State Compensation Board advised that the difference between an employee and an independent contractor is an extremely 'grey area' open to disputes which at this stage could only be settled by a court ruling. If some commonly used criteria are applied (supplies own tools, nominates the time work will be done, works for several different people) attendants would appear to be employees.

This uncertainty, together with the considerably greater cost of purchasing individual policies, indicates the need for negotiations to arrange a "head policy" for any future allowance scheme.

5.1.4 Attendants' Travel Reimbursement

Aides employed by the Home Care Service of NSW are reimbursed (currently at 23 cents per kilometre) for travel within the specified branch's area. Typically aides travel between clients during the course of their work, reimbursement under these circumstances being the norm in most avenues of employment. Payment for time spent travelling is another 'grey area'. Whilst no specific payment is made, flexibility of starting and finishing times frequently means travel time is paid for. Aides working for perhaps one client only, such that all travel is between home and place of employment are still reimbursed for travel.

Initially HCS policy on this issue was adopted in principle by the pilot. However $1 per hour assessed (in lieu of 23 cents/km actually travelled) was being paid in the allowance model to circumvent the forseen need to constantly vary the size of allowance cheques.

Participants in outlying areas where attendants were required to travel relatively longer distances found the flat rate inadequate and requested a reversion to normal HCS practice. This was agreed to by the Management Committee within one month of the pilot commencing. At that time each participant advised the co-ordinator of the travel reimbursement required by their current attendants. Cheques were adjusted to include this amount. The co-ordinator was to be advised as changes in requirements occurred e.g. when a change of staff occurred.

The whole question of travel reimbursement in the allowance model was entirely unsatisfactory for the following reasons:-

- reimbursement was not restricted to travel within a set area
- no attendant worked for more than one 'client', each participant having independently hired attendants, hence all travel being paid for was between attendant's home and place of employment. Payment for travel may be necessary for casual work like this with no guaranteed minimum hours in a shift but the necessity for it was not adequately tested in this pilot.
- the amount paid out for travel varied depending on which particular schedule of attendants was used in any given week, even when there had been no actual turnover in staff, and when there were staff changes.
- the travel component of allowance cheques remained unchanged throughout the pilot for all except five participants one of whom requested increases on two occasions, the others one increase each. Two people's increases were in conjunction with increased hours.

The amounts included in allowances for the travel component and the average amounts which were paid to attendants are given in Table 5.1.

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Table 5.1: Travel Reimbursement to Attendants in the Allowance Model

Weekly Travel Component in Allowance $	Travel Component per assessed hour $	**Average Travel cost per hour worked paid to attendants $
13.68	.51	.36
NIL	NIL	NIL
22.94	1.00	1.21
13.80	.71	.72
24.84	1.13	.95
24.46	.87	NIL
89.70	4.27	3.19
44.16	2.26	NIL *(2.00)
82.34	3.23	2.10
29.29	1.78	.97
NIL	NIL	NIL
6.44	.46	.46
12.88	.92	.92
12.88	.81	.22
20.70	.74	.43
	$\bar{X} = 1.25$	$\bar{X} = 0.90$

*paid a flat hourly rate of $10.00

** average amount paid out for travel over a six month period - information supplied by participants on weekly timesheets (see Section 5.1.7).

Travel cost per hour is very dependent on the lengths of shifts worked. The distribution of shift lengths in the allowance model is shown in Table 5.2

Table 5.2: Allowance Model Shifts

Length of Shift (hours)	Percentage of Total shifts worked
.75	10.2
1	36.2
1.5	10.2
2	23.0
2.5	6.6
3	10.7
4	2.0
>4	1.0

5.1.5 Attendant Management Training for Participants

The Co-ordinator, in consultation with members of Disabled People's International, (NSW), prepared an Attendant Management Manual and a Workshop session which was presented on two occasions. Twelve allowance participants attended one or other workshop session. All allowance participants received a copy of the manual, included in this report at Appendix C. The topics covered by both the manual and the workshop included:-

- finding attendants
- interviewing
- contracts
- rosters
- responsibilities

The co-ordinator made it clear that she was only too willing to provide assistance with any aspect of attendant management, should participants request it.

5.1.6 Employment of Attendants

The characteristics of the attendants employed in both the service and allowance models are presented in Section 5.3. More than two thirds of the attendants initially employed by allowance participants had been found through a friend or were already known to the participant. This declined over the course of the pilot as a greater number of replacement attendants were located through advertisements.

Co-ordinator's Assistance

Response to individual advertisements was in general good, resulting in little need for participants to seek the co-ordinator's assistance. One advertisement bringing no responses at all, when reworded by the co-ordinator, was much more successful. One family, preferring not to advertise but to find attendants through known contacts (priest, friends), found it useful during a family crisis to have the co-ordinator suggest a suitable attendant. The co-ordinator was also asked to receive the initial responses to an advertisement placed by a participant after she had encountered a poor acceptance by some enquirers, due to her decreased speech clarity. The same person encountered difficulties from time to time, particularly when spouse was temporarily away from home on business, in finding people to stay overnight and arranging backups for absent attendants. At times the co-ordinator provided considerable support and assistance to this participant.

A fourth participant required the co-ordinator's encouragement not to withdraw from the pilot when her initial advertisement did not attract the "right kind of people".

Numbers of concurrent attendants
The number of concurrent attendants used, remained stable for all except one participant who, when his single attendant resigned after nineteen months, decided to divide his hours between three new attendants. Two participants each employed one attendant only for the duration of the pilot. The number of attendants available influenced the ease with which a replacement could be found to cover an attendant's absence.

Table 5.3: Number of Attendants - Allowance Participants

Group	Allocated hours (most recent)	Number of attendants		
		Concurrent when commenced in pilot	Current as of 31.10.85	Total during pilot
A1	22	3	3	5
A1	14	1	3	6
A1	16	2	2	4
A1	21	1	1	1
A1	19.5	3	3	4
A1	21	5	5	10
A1	14	1	1	1
A2	11	5	-	5
A2	22	2 (+5 standby)	2 (+4 standby)	7
A2	21	3	3	8
A2	16.5	6	7	21
A2	27	4	4	9
A2	25.5	3	3	6
A2	28	2	3	7
A2	28	4	4	14
A2	42	3	3	10

Employment of relatives as attendants
A small number of relatives of participants were employed as regular attendants. One participant employed his two brothers, living in the same household as himself, for approximately one third of his weekly hours; a sister-in-law in a participant's household was employed for 10% of her hours; a father-in-law not living in the participant's household provided all the attendant care for that participant for the pilot's duration and a mother-in-law was a back-up attendant for another participant on rare occasions. Approval to employ these relatives was not sought, nor was it required by the agreement entered into when participants accepted an allowance.

Although permission was not required it was sought by three others receiving allowances, to employ a relative living in their own household; a spouse, a brother and a sister respectively. Each had, for many years prior to the pilot, provided extensive voluntary care. The Co-ordinator indicated that she felt the employment of relatives was not desirable.

When a household relative 'filled in' for an absent attendant, one participant paid what he would have paid the attendant; most did not. Either way, care must be provided. Money cannot be saved by reducing the amount of care provided but may be saved when relatives do it voluntarily.

Participants' current use of family members and their opinions about future policy on this issue are shown in Table 5.4.

Table 5.4: Employment of family members

Model	Current situation	Future choice
Allowance 1		
	No	No, leads to greater independence less likely to be abused in the care if outsiders employed
	No	Yes
	No	Yes if capable and living close by
	Yes	Yes; more families would benefit
	Yes (brother)	No but prefer at night as more personal
	No	No; wouldn't now, but would have liked to pay sons when they did it years ago
	No	No; rather outsiders and keep family the way it is now
Allowance 2		
	No	No, wants to preserve normal interactions
	No-Yes fill in spouse	No, never on regular basis, but yes if for fill in
	No	No, creates unnecessary difficulties but if fill in should be paid
	No	No, because they would feel bad about accepting the money - would not seem like home anymore
	No	No - keep separate
	No	No never
	No	No definitely outsiders and not friends/relatives
	No	No lead to fights - parents no longer capable

5.1.7 Accountability

Participants were responsible for keeping accurate records of moneys received and disbursed, such records to be available to the evaluation team when requested.

To this end a record of expenditure for four consecutive weeks was required by the evaluation team in February 1984, July 1984 and January 1985. Weekly timesheets showing hours worked, wages and travel paid to each attendant, signed by attendants and participant were forwarded to the evaluation team for a period of nine months from May 1985 to January 1986. Analysis of individuals' expenditure for a six month period is presented in Section 7.

5.1.8 Variation in weekly hours used

It has been claimed that an allowance provides greater flexibility in the use of hours in that unused hours (money) may be accumulated for use at a later time. Such accumulation is not currently possible under the Home Care Service which provides up to the agreed hours allocated in any one week, with unused hours reverting to the branch.

The patterns of use for each participant, as indicated by their timesheets, are shown in Table 5.5.

The reasons for complete non-use of hours by some participants in occasional weeks were hospital admissions, a gap between an attendant resigning and a replacement starting, holidays for which other family members provided care and institutional respite care. Respite care, an alternative source of attendant care, was paid for from allowances. Ignoring for the moment the government subsidy paid for respite care, the cost to participants for such care was less than the allowance received.

Table 5.5: Variation in use of hours

Allowance (Hours/Week)	Hours/Week purchased			
	minimum	maximum	mean	standard deviation
22	18	28.5	22.1	2.9
14	0	15.25	11.7	3.6
16	0	16.5	10.3	3.9
21	0	26	18.9	6.6
19.5	19.5	20.5	19.8	0.3
21	21.5	21.5	21.5	0
14	11.5	14	12.8	0.8
42	22.25	64	41.0	11.4
22	17	24	19.7	2.3
21	4	22	17.7	3.7
16.5	12	20.25	16.3	2.3
27	23	27.5	26.4	1.4
25.5	13	28.5	24.5	3.0
28	24	28	25.4	1.4
28	27.5	34	28.9	1.8

The extent of variation confirms the usefulness of a flexible system which allows accumulation of hours or money.

The under-utilization of hours (compare allowance hours/week with mean hours/week purchased) should not cast doubt on the validity of assessed hours, given the above reasons for non-use of hours. The variation in weekly hours used reflects temporary absences from home, fluctuations in the extent of use of voluntary care and patterns of activities which have cycle lengths in excess of one week.

5.1.9 Expenditure of Allowance Moneys on items other than attendant care

Three participants spent money on items related to their disability, other than attendant care.

- $176 for a commode chair which had been ordered through PADP nine months before and participant simply gave up waiting
- $673.78 for building modifications (lowered power points, hot water, ramp, shower extension, window, medical supplies)
- $40 for wheelchair cushion

5.1.10 Additional services used

All participants except one used the "free" services of other household members.

Three used the HCS for housecleaning service (3.5, 3 and 5 hours/week).
Subsidised taxis were relied upon to a greater or lesser extent by all participants.

Four people occupied a hospital bed for 14, 24, 3 and 7 days. Free care, Home Care Service and hospital care cost implications are considered in Section 7.

Assistance with selecting equipment and arranging for housing modifications, provided by the occupational therapist is documented in Section 4.

5.1.11 Management of attendants

Training

All training required was provided by participants and/or other household members. The co-ordinator's offer of training on any aspect of attendant care, made to participants and not directly to attendants, was accepted by one attendant who did not agree with her employer about certain aspects of bowel care. Arrangements were made for an individual training session for this attendant, on bowel care and lifting techniques. Allowance participants were invited to send their attendants to a training session on safe lifting techniques being arranged for service model attendants. Three allowance model attendants were present for this session.

Tasks performed by the attendants
Light meal preparation (particularly breakfast)
Tidying/organising
Transferring
Showering/dressing
Enemas
Catheter care, uredomes, leg bags
Grooming
Feeding
Cleaning bathroom after showering
Shopping
Driving
Lawn mowing, car washing
Washing, ironing
Assistance with a hobby
Accompanying to medical appointments
Accompanying to swimming centre, assisting with swimming

The full range of tasks was not carried out by all attendants or for all participants. Whilst the majority of attendant time was used for personal care, other household tasks were fitted in by 'trading off' against personal care provided by household members or by integrating such tasks with personal care to avoid unused 'waiting time' as described in detail in Section 4.

It must be emphasized that assessed hours were based on the performance of personal care tasks only. The additional non-personal care tasks listed above, which of course participants cannot do for themselves, were fitted into attendant hours available, only because there was otherwise wasted waiting time or because household members did some of the personal care instead.

Examples of rosters and tasks performed for individual participants are included in the case studies presented in Section 6.

Rates of Pay

Although allowances had been calculated on the basis of the Home Care Service aides' rate of pay, allowance participants were completely free to pay whatever rate they saw fit. Few in fact paid other than the Home Care Service rate. The following variations were reported on timesheets (July '85 to January '86):-

- $4/hour to school students for hairwashing (mean rate paid across all attendants by this participant was $7.39/hour)
- $5/hour to a school student for assistance transfering into car and $10/hour to some attendants when no extra payment was made for travel (mean rate paid across all attendants by this participant was $9.48/hour)
- $8/hour to all attendants when the allowance rate was $8.02/hour and $7.00/hour when the allowance rate was $7.81/hour (mean rate paid across all attendants by this participant was $7.30/hour)
- $8/hour to all attendants when the allowance rate was $8.02/hour; had previously paid $7.81/hour when that was the allowance rate (mean rate paid across all attendants by this participant was $7.99/hour)
- $7/hour to all attendants
- $5/hour occasionally (mean rate paid across all attendants by this participant was $7.93/hour)

The mean rate paid over the same period of time by participants who invariably paid the allowance rate to all attendants was $8.00/hour. The extent of the above variations can thus be seen to have been limited.

Role of family members acting on behalf of participants in attendant care management

One participant did not engage in attendant management at all, but remained dependent on a family member to make all arrangements. Communication difficulties made it impossible for the evaluator to

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assess whether this participant had the intellectual capacity or the desire to manage her own affairs. If she did not, her inclusion in the pilot was in error.

Two participants with communication difficulties, one of whom was also blind, were able to work through family members to make attendant care arrangements with complete control remaining in their own hands.

One young person received intermittent parental help at his own request, such help falling into the category of training, the need for which would in time disappear.

The significance of the availability of such assistance for some allowance recipients should not be underestimated. In the absence of an appropriate 'advocate', a Co-ordinator may be required to assist with attendant management.

Back up arrangements

Attendants' reliability was reported to be excellent, any absences being arranged ahead whenever possible. Three methods were used to arrange care in the absence of a regular attendant. The particular method used was at least partly dependent on living arrangements:-

i) household members filled in
ii) other regular attendants filled in
iii) attendants only ever used as backups were called in.

The last method, most necessary for people totally dependent on one attendant, was the most difficult to maintain. A regular set of three or four attendants was found to provide the best source of back up care as it was unusual for none of the set to be available at a particular time.

5.1.12 Co-ordinator's role in the allowance model

The co-ordinator's role included administration of the payment of allowances, providing assistance to locate attendants in the specific instances already documented and negotiating arrangements for the provision of care at the pilot's conclusion. Isolated complaints were received by the co-ordinator from allowance model attendants (3) but the participants concerned were happy to handle the matter themselves. In two of these cases, in which the participants' assessment of the situation was, that perhaps it was time to find a new attendant, the situation was resolved by the attendant's resignation or dismissal. One attendant who, unknown to her employer, contacted the co-ordinator on several occasions to complain about work times and duties, has continued to work for that employer for the entire pilot period. The co-ordinator, on each occasion, advised the attendant to discuss the problems with the employer.

The extent of counselling and support provided was difficult to determine in the case of one co-ordinator as she was personally known to several participants already and was frequently in contact with allowance participants in relation to their anxiety concerning future provision of attendant care, particularly in the pilot's later stages.

This co-ordinator believed that some allowance recipients were not using their allowances to best advantage in terms of increasing their independence and felt intervention would have been useful in this regard.

5.1.13 Conclusion

The pilot study has provided the opportunity for this small group of severely physically disabled people to demonstrate that they are capable of managing all aspect of their own attendant care arrangements, given only sufficient funds to do so. In response to the question "How would you feel about receiving an allowance even if this meant no support staff would be available?", thirteen were confident that this would meet their needs exactly, one relative acting on a participant's behalf was similarly confident and two (both previously inexperienced) indicated they would prefer the availability of support and assistance if required.

5.2 The service model

The eight people in this model used care provided by attendants who were responsible to the Co-ordinator. Attendants employed on a casual basis, were paid at a fixed hourly rate, reimbursed for travel at a fixed rate per kilometre and covered by a workers' compensation insurance policy taken out by the co-ordinator.

Being employees of an agency, responsibility for their working conditions and for the satisfaction of clients, rested with the agency. Orientation and training programs for these attendants were as much, if not more so, for the benefit and protection of the attendants themselves as they were for the benefit and protection of clients.

Assessed hours represented the upper limits of the weekly amounts of service which could be provided, on average, unless additional hours were authorised via reassesment i.e. unused hours could be accumulated. This feature is in contrast to the principle operating in some existing service agencies.

5.2.1 Employment of attendants

Only two participants in this model requested the employment of persons known to them already, in the first instance. A brother's fiancee was hired to provide two thirds of one participant's hours; a boarder and a HCS aide who had previously cooked and cleaned in the household were hired for another. The remaining attendants initially hired were located via advertisements the co-ordinator placed in local newspapers in the seven suburban areas in which participants lived. The first Co-ordinator finding it impractical to personally interview all respondents to these advertisements, supplied each participant with a list of potential attendants, selected on the basis of a telephone interview, for him to contact, interview and select.

A large number of telephone calls was received in response to the advertisements, however, some callers were no longer interested once the job was described. The rates of males to females amongst the 242 suitable respondents was 1:4, with some variation by area, the area with the greatest proportion of males being the inner western suburbs and the lowest, Blacktown and the northern beaches. Ages ranged from 16 to 70, with 50% aged less than 30 years and 75% less than 40 years. Two thirds had previous experience with this type of work (33% were actually qualified nurses or nursing aides) one third were already employed full or part time, half were married and three quarters had the use of a car.

Additional or replacement attendants during the first co-ordinator's term in office were located by participants themselves (at their own request) via friends, advertisements or selecting people already known. Application forms were completed and forwarded to the co-ordinator. Each attendant was given a copy of a duty statement prepared by the co-ordinator (see Figure 5.1).

The second co-ordinator however was actively involved in advertising for and interviewing prospective attendants together with the participants concerned, leaving the final choice to them. The number of concurrent attendants used by each person in the Service Model is shown in Table 5.6. The number of attendants available influenced the ease with which a replacement could be found to cover an attendant's absence (see Section 5.2.7). Only one relative of a participant, a brother's fiancee, later sister-in-law, was employed in this model.

THE ATTENDANT CARE PILOT STUDY

POSITION: Attendant

RESPONSIBLE TO: Co-ordinator of Attendant Care Pilot Study.

DUTIES: Duties will vary according to the needs of the individual.

i) The main responsibility of an attendant is to provide personal care assistance which may include helping the disabled person in and out of bed and wheelchairs, on and off shower chairs, commodes, helping the person with showering, toiletting, grooming, feeding and in some instances light meal preparation.

ii) To bring to the attention of the Co-ordinator:

(a) any observed changes in the well-being or situation of any clients
(b) queries concerning the nature of assistance provided.
(c) requests for changes in service provided.
(d) any dissatisfaction with personal/working relationship between attendant and client.

iii) To respect the client's rights to control their own lives and homes in accordance with their individual values and standards.

iv) To maintain confidentiality.

v) To advise the Co-ordinator of any medical emergencies that arise in relation to clients, as soon as the doctor and next of kin have been informed.

vi) To ensure timesheets are correctly filled in and hours worked are filled in and signed by the client. Timesheets are to be handed in on a weekly basis.

vii) To report any absence from work to the Co-ordinator as soon as possible.

viii) When providing a replacement for self, be sure:

(a) the client agrees to any person arranged to "stand-in".
(b) that "stand-in" is registered with Co-ordinator and has completed the necessary forms.
(c) that client is given the opportunity to find own "stand-in" if he chooses.

ix) To adhere to all work schedules arranged between the client and Co-ordinator and times set by client.

x) To report immediately any damage to client's property or person arising from the assistance provided.

xi) To report immediately to the Co-ordinator any personal injuries sustained whilst carrying out duties for clients or travelling to or from client's homes.

Figure 5.1: Duty Statements supplied to participants in service model to show their attendants/prospective attendants

Table 5.6: Number of concurrent attendants - service participants

Allocated hours (most recent)	Number of attendants		
	Current when commenced in pilot	Current as at 31.10.85	Total during Pilot (n=49)
23	2	3	6
21	2	4	6
16	4	5	7
18	3	3	6
15.5	1	1	2
17.5	6	5	11
18	2	1	2
24	4	3	9

5.2.2 Training of Service Model Attendants

Training comprises, in practice, three discrete elements:

i) orientation to the job when first employed
ii) practical instruction in 'what to do' and 'how to do it'
iii) in-service training on selected topics

i) and ii) must occur prior to and on commencement of duties
iii) can occur at any time.

The exigencies of attendant employment meant that attendants rarely had the opportunity to attend a formal orientation session prior to taking up duties, engaging instead in a discussion of relevant issues with the co-ordinator, either in person or by telephone. Practical instruction, in the first instance, was provided by the participants, other household members or other attendants already working for the person in question. A quarter of service model attendants were trained nurses, thus reducing the need for practical instruction.

The co-ordinator was available by phone to advise attendants on any aspect of attendant work, some availing themselves of this opportunity for contact, some not doing so. Some of the participants, wishing to handle matters directly themselves, discouraged their attendants from taking problems to the co-ordinator.

Formal training sessions, which attendants were paid to attend, were difficult to schedule at times and locations to suit all.

Table 5.7: Formal Attendant Training Sessions for the Service Model

Date	Topic	Total Attendants (service) employed at that time	Number who attended session	
			service	allowance
16.4.84	Safe lifting	13	1	3
27.2.85	Group discussion	20	12	0
28.6.85	Spinal Injuries	20	6	0
5.7.85	Safe lifting	20	4	0

5.2.3 Variation in weekly hours used

Two significant characteristics of this service model were the provision for carrying forward unused hours for later use and for employment of attendants in locations other than home e.g. when on holidays.

Implicit in the carry forward provision was the expectation that the overall average hours per week used would not exceed the number allocated by the occupational therapist. The average hours used by three people exceeded their allocated hours by the amounts shown in Table 5.8. Ad hoc granting of extra hours for non-routine events (e.g. attending a medical appointment, a short term stock market course, selecting a computer to purchase etc) accounts for the over-run.

It appears that monitoring the average hours used was difficult in the absence of the use of a computerised accounting system but would be essential in the management of a future attendant care scheme. Requests for hours in excess of those allocated calls for a formal reassessment.

Table 5.8: Variation in use of hours

Allocated hours	Hours/week used			
	minimum	maximum	mean	standard deviation
23	0	27	23.92	5.13
21	15.5	24.5	21.63	1.57
16	6.5	27	14.82	3.87
18	6	19.5	15.88	4.01
15.5	0	20	14.02	4.04
17.5	3	23.5	13.43	6.75
18	0	27.5	19.11	7.45
20.5	0	25	19.91	5.48

5.2.4 Tasks performed

The duty statement given to attendants emphasized that the main tasks were to be strictly personal care assistance, the specific tasks varying according to the needs of the individual. During the first eight months of the pilot this guideline was adhered to fairly strictly. One attendant in fact resigned because she was asked by a participant to perform household chores as well as personal care, something she had not anticipated when accepting the job. Other household members took care of all housekeeping tasks for service participants with Home Care Service input in two cases. A limited amount of driving was the only extra task undertaken by attendants.

Some inefficiencies in use of paid hours resulted from limiting the tasks to be done to personal care only. Attendants in some instances sat and waited during a bowel routine for as long as three quarters of an hour. This is discussed in more detail in Section 4.

Later in the pilot, attendants in two households were engaged in providing a more integrated set of services including both personal care and housekeeping tasks.

5.2.5 Travel reimbursement

As was the case in the allowance model, travel reimbursement was not strictly limited to travel within a specified area despite considerable efforts to employ attendants living as close as possible to participants. The service model overall was less successful in this respect than were the allowance model participants, as can be seen by comparing Tables 5.1 and 5.9, allowing for some differences in distribution of shift lengths in the two models (compare Tables 5.2 and 5.10).

Table 5.9: Service model travel reimbursement for the financial year 1984/85

Total hours	Travel reimbursed ($)	Cost of travel per hour worked ($)
1244	2977.46	2.39
1125	2647.99	2.35
207.5*	614.01	2.96
826	1715.80	2.08
729	809.35	1.11
698.5	1509.60	2.16
994	3389.15	3.41
1035.5	1526.27	1.47
		$\bar{X}$ = 2.24

* service provided for portion of year only

Travel cost per hour worked is very dependent on the lengths of shifts worked. The distribution of shift lengths in the service model is shown in Table 5.10.

Table 5.10: Service model attendant's shift lengths

Length of shift (Hours)	Percentage of total shifts worked
.75	2.9
1	52.9
1.5	21.6
2	20.6
3	2.0

5.2.5 Additional services used by Service Model participants

All participants had access to the 'free' services provided by other household members but in two cases this was not available for the entire pilot period. One person found he was able to live alone with the same attendant hours as previously used when sharing the house with two able bodied people, with the addition of 6 hours per week housekeeping (mainly cooking) provided by HCS. Attendants, neighbours and a relative appeared to be providing voluntary assistance as well, on a small scale (five minutes here and there), but it is difficult to distinguish between "assistance" and just being neighbourly.

The other household, losing its able bodied members, was reduced to two people, equally severely disabled. Again, additional input of HCS hours (7 hours/week each) and an increase in attendant care hours from 20.5 to 24 per week was sufficient to meet all needs (in fact some 'trading' of personal care hours and Home Care Service hours within the household meant that this participant really only used two hours of Home Care Service assistance per week). Home Care Service was providing 14 hours personal care for the second disabled household member, giving an overall total of 52 hours per week of paid assistance to a household of 2 people with severe physical disabilities.

One other household was receiving 1.5 hours/week from HCS to relieve a spouse.

5.2.7 Back-up arrangements

Service model participants did not have access to a pool of attendants for use in emergencies or to fill gaps between an attendant leaving and a replacement starting. This was due partly to their widely dispersed locations and partly to the principle of allowing each participant to select his own particular set of attendants. In two instances the co-ordinator arranged for temporary service through a private nursing agency. Use of household members was the ultimate fall back position, this being the preferred option chosen by the four participants with household members capable of providing the care. Three always arranged backup amongst their group of attendants and one family was critical of the lack of suitable backup arrangements, which had resulted in family members and an attendant filling in unwillingly.

5.2.8 Conflicting roles for a service Co-ordinator

The best interests of attendants and participants are not necessarily coincident. The need to serve both sometimes leaves a co-ordinator subject to criticism of interference on the one hand and neglect on the other. Co-ordinator and participant may disagree on the relative merits of a particular attendant.

A co-ordinator's decision to facilitate the move towards what she perceives as greater independence may not be acceptable if too much is attempted too soon.

5.2.9 Participants' future preferences for Service or Allowance Model of Attendant Care

In response to the question "How would you feel about receiving an allowance even if this meant no support staff would be available?", four service model participants indicated that this would "not present any problems at all" and that if given the choice now they would opt for an allowance. Four participants said they would prefer to continue in a service model which provides contact, support services and backup assistance.

The move towards preference for an allowance, after experience in a service model could be interpreted as part of a general move towards increased independence. Such interpretation can, however, only be conjecture at this stage.

5.3 The Attendants

5.3.1 Previous Research

Some 168 people have been employed as attendants in this pilot project. Previously, little attention has been focused on the characteristics of attendants, with the few reported studies concentrating on negative aspects such as job dissatisfaction and high turnover rates.

Atkins, Meyer and Smith (1982), examining why attendant turnover rates were so high in Wisconsin, found no good predictors of length of employment but concluded that, to overcome the turnover problem, attendants should be highly qualified and the job made to seem important. Wage levels, largely determined by government payments of one form or another, although contributing to job satisfaction, are not, according to Smith and Meyer in an earlier paper (1981) the only factor and suggest that psychological rewards must be created to dignify and professionalise the attendant role. Atkins et al's (1982) attendants were predominantly female students, single, with no dependents, under 27 years of age, had had no previous contact with disabled people and typically a change in timetable was the reason given for resigning.

Stelmach, Postma, Goldstein and Shepard (1981) found a much more stable picture amongst a group of attendants working in the San Francisco Bay Area where attendant work had been available for a long time. Although still predominantly female, less than one third were students and nearly two thirds had other current jobs (mostly other attendant jobs) and nearly half had at least five previous attendant jobs. The researchers found low levels of dissatisfaction and an extremely varied population doing attendant care work. An interesting age correlate emerges in Hutchins, Thornock, Lindgren and Parks'(1978) study of attendants working in Seattle. Younger attendants viewed attendant work as a 'temporary expediency' while older attendants were more likely to see it as a permanent line of work involving working in more than one position at a time. This relationship will be raised again in relation to disabled employers' preferences with respect to 'professional' and 'casual' attendant carers. Clients of the Boston Centre for Independent Living are reported by Kahn (1980) to experience unsatisfactorily high turnover rates which they directly attribute to the low rates of pay.

Attendants working for severely impaired recipients in California's In Home Supportive Services program (IHSS) which had been in operation for twenty four years at the time of the most recent characteristics survey (State of California, Department of Social Services,1983) have an average length of employment of 27.5 months. Only two thirds of such attendants, however were described as 'personal attendants', the remainder presumably performing housework related tasks only. The typical attendant in the IHSS program is an older woman who is a former homemaker.

The Personal Care Workers Study (1984) in Northcote (Melbourne, Australia) was restricted in its first phase, by the nature of its funding, to employing people who had been registered as unemployed for the preceding six months and was also obliged to provide 30 hours of work per person per week including training. The description of these attendants is therefore of little value in predicting the range of people in the Australian context likely to seek work as attendants, or the range of acceptable hours per week and numbers of employers.

The Home Care Service of NSW, a government funded agency providing a variety of in-home services to aged and disabled people, entered the personal care field on a small scale exploratory basis in 1979, the service having grown dramatically in the intervening years. Unfortunately there has been no formal survey of attendants employed by this agency, but Co-ordinators report an extremely varied population doing personal care work.

5.3.2 Attendants employed in this Project

Information was sought from the 168 attendants employed by the 24 study participants between mid January 1984 and October 1985 (a period of 21.5 months). Participants commenced employing attendants at different times giving varying lengths of involvement within the 21.5 month period. The mean length of involvement was 18.5 months (s.d. = 4.45).

All participants (both service and allowance) were asked to provide every attendant employed by them during the study period with a questionnaire which, when completed, was to be returned by the attendant in the prepaid envelope supplied, to the evaluation team. Questionnaires were received from 128 attendants giving a 76% return rate overall (Allowance 1 - 84%, Allowance 2 - 75%, Service 74%). Eleven participants managed to get all of their attendants to return forms, six had only one or two missing and six each had several missing. Only one attendant worked for more than one study participant.

5.3.2.1 Personal characteristics

The typical attendant is female, aged between 26 and 45, not presently married, has no dependents, has reached School Certificate level of education, had previously had contact with disabled people (a relative, work or other), found this job through an advertisement and has no other job apart from this one.

Nevertheless, a wide diversity of people has been employed as attendants, as the following tables indicate.

Table 5.11: Attendants: Age

Age Group	Attendants					
	all		service		allowance	
	N	%	N	%	N	%
Total	121	100	32	100	89	100
25 or younger	40	33.1	10	31.2	30	33.7
26 to 45	65	53.7	20	62.5	45	50.6
46 to 65	15	12.4	1	3.1	14	15.7
66 or older	1	0.8	1	3.1	0	0

Table 5.12: Attendants: Marital Status

Marital Status	Attendants					
	all		service		allowance	
	N	%	N	%	N	%
Total	122	100	33	100	89	100
Single	56	45.9	12	36.4	44	49.4
Married	37	30.3	13	39.4	24	27.0
Wid/Sep/Divorced	29	23.8	8	24.2	21	23.6

Nearly two thirds have no dependents and a quarter have two or more. Education levels across the full spectrum are represented from those with no School Certificate (or equivalent) to those with a university degree. There is no clear relationship between education level and whether or not the person has another full or part time job.

Table 5.13: Attendants: Education Level

Education level	Attendants					
	all		service		allowance	
	N	%	N	%	N	%
Total	121	100	32	100	89	100
No Certificate	18	14.9	6	18.7	12	13.5
School Certificate	39	32.2	6	18.7	33	37.1
Higher School Cert.	27	22.3	5	15.6	22	24.7
Technical College Cert.	5	4.1	2	6.2	3	3.4
Nursing Certificate	19	15.7	9	28.1	10	11.2
Diploma/Degree	13	10.7	4	12.5	9	10.1

The higher proportion of trained nurses in the service model was not the consequence of a deliberate policy on the part of either co-ordinator. Service model participants had the final say in the selection of all attendants; the greater observed proportion of nurses may reflect some participants' preferences.

Nearly two thirds of attendants were female, a situation probably arising from the general characteristics of female employment such as availability for casual work and more specific factors such as the clear preference of females with disabilities for female attendants only (six of the seven female participants employed females exclusively), while only two males had employed only male attendants). A higher proportion of males were in the younger age group, than was the case for females.

Two thirds of attendants had had previous contact with people with disabilities through work (41%), a relative (9.8%) or some other link (13.1%) but whereas two thirds of people who found the job through an advertisement had had previous contact, only half finding the job through a friend had done so. A greater proportion of allowance model attendants had had no previous contact with disabled people.

Table 5.14: Attendants: Previous contact with Disabled People

Previous contact	Attendants					
	all		service		allowance	
	N	%	N	%	N	%
None	44	36.1	5	15.2	39	43.8
Relative	12	9.8	2	6.1	10	11.2
Work	50	41.0	20	60.6	30	33.7
Other	16	13.1	6	18.2	10	11.2
Total	122	100	33	100	89	100

Table 5.15: Attendants: Previous contact with people with disabilities and how this job was found (n = 122)

		How this job was found		
		Advertisement	Through a friend	Already knew employer
Previous contact with disability	None	24	14	6
	Relative	6	2	4
	Work	27	8	15
	Other	10	1	5

Approximately half of the attendants have no other jobs, 9% work for the Home Care Service of NSW and one third have other full or part time jobs. The proportions having other full or part time jobs are the same within each model.

Table 5.16: Attendants: Other Jobs

Other jobs held at time	Attendants					
	All		Service		Allowance	
	N	%	N	%	N	%
None	68	55.3	20	58.8	48	53.9
HCS aide	11	8.9	3	8.8	8	9.0
Other P/T	25	20.3	4	11.8	21	23.6
Other F/T	19	15.4	7	20.6	12	13.5
Total	123	100	34	100	89	100

5.3.2.2 Job Characteristics

How attendants found the job

Service model participants had the same freedom as allowance model participants to nominate and select attendants. The co-ordinator placed newspaper advertisements only at a participant's request. Despite this, a greater proportion of service model attendants were located via an advertisement and a correspondingly greater proportion of allowance model attendants already knew the participant.

Table 5.17: Attendants: How this job was found

	Attendants					
	all		service		allowance	
	N	%	N	%	N	%
Total	123	100	34	100	89	100
Advertised	68	55.3	22	64.7	46	51.7
Through a friend	25	20.3	7	20.6	18	20.2
Knew participant	30	24.4	5	14.7	25	28.1

Proximity to participant's residence

The "average attendant", lives 8 kms from his employer's home and takes approximately fifteen minutes to travel there by private car. The wide variation in the sample is hidden by these averages. Some "back-up" attendants, not working on a regular basis live up to 32 kms away!

Table 5.18: Attendants: Travel to Work

	Mean	Standard Deviation	Median	Mode	Minimum	Maximum
Distance (kms)	7.4	6.7	5.0	5.0	0	32.0
Travel Time (minutes)	15	11	10	10	0	60

The maximum travel times are due to method of travel (public transport) rather than distance.

Table 5.19: Attendants: Method of Travel

Method of Travel	Attendants					
	all		service		allowance	
	N	%	N	%	N	%
Total	120	100	33	100	87	100
Walk	18	15.0	2	6.1	16	18.4
Car	90	75.0	30	90.9	60	69.0
Public Transport	8	6.7	0	0	8	9.2
Live in employers home	3	2.5	1	3.0	2	2.3
Taxi	1	0.8	0	0	1	1.1

It should be noted that travel time was not included in hours worked; those driving a car were reimbursed at a fixed per kilometre rate and fares were reimbursed for those using public transport.

Work Timetable

The typical attendant works 5 to 6 hours a week in 3 to 5 shifts outside normal business hours. Six people have been the sole attendants (for five different participants) working morning and evening seven days a week, (3 people, 18, 14 and 21 hours per week) or mornings only (3 people, 15, 15 and 14 hours per week). All of these people worked continuously for many months, three for the entire project period.

Table 5.20: Attendants: Hours worked per week by regular attendants

Hours/Week	% of sample (N=128)
5 or less	62
6 to 10	25
11 to 15	10
16 to 21	3

Table 5.21: Attendants: Shifts/week worked by regular attendants

Shifts/Week	% of sample (N=113)
1	13.9
2	11.3
3	18.3
4	16.5
5	18.3
6 - 10	14.7
11 - 14	5.2

Attendants did not, in general, have the opportunity to work for more than one client, even in the service model. The second co-ordinator did not encourage the practice on the grounds that availability of an attendant to an individual client could be restricted and the risk of lack of confidentiality would be increased.

The participants' desire to divide their hours between several attendants to facilitate back up arrangements, limited the earnings of an individual attendant unless he could work for more than one client. Some attendants were working as aides for the Home Care Service (9% of sample) at the time of accepting a position in the pilot, while others, having been introduced to this type of work through the pilot, sought extra work with the Home Care Service.

There is room in this field of employment to meet the needs of both disabled employers and attendants, on this issue, if intentions of both parties are made clear, as illustrated in Figure 5.2.

Participants	Attendants	
	Only wanting a few hours	Wanting to work a large number of hours
Want attendants who do not work for other disabled people	Suitable match	Unsuitable match
Do not mind if attendants work for other disabled people	Suitable match	Suitable match

Figure 5.2: Matching the preferences of attendants and participants

Turnover Rates

Of the 128 attendants for whom information was available, 69 were still employed at the time these statistics were compiled and 59 had left the job, seven having been dismissed (3 service, 4 allowance) and 52 having resigned. One third of those still employed had been so ever since their participant joined the pilot.

Periods of employment for those who discontinued varied from one week to nineteen months. There was a tendency, as can be seen in Table 5.22, for people to either leave within a month of starting or to continue for many months. Males outnumbered females in the group leaving within a month of starting.

Table 5.22: Length of employment of attendants who discontinued before pilot finished (n = 59)

Length of employment (months)	Allowance % (n = 40)	Service % (n = 19)	Total % (n = 59)
1 or less	22.7	20	21.9
Between 1 and 3	27.3	30	28.2
4 to 5	13.6	20	15.6
6 to 12	20.5	30	23.4
More than 12	15.9	0	10.9

Resignation after a relatively short period was not necessarily unanticipated or a reflection of any dissatisfaction. One allowance participant in particular employed several students over their vacation, knowing it would be short term.

Reasons for leaving appeared to have little to do with the participant or the actual job but rather, reflected some attendants' views of this work as a temporary expediency. This view also suited some participants who were seeking not 'professional' attendants but people busy with their own concerns and interests, who, for whatever reason, found it suited them to work as attendants for a time. Other participants preferred the security of continuity and the genuine friendships that sometimes developed.

Reasons given for resigning included finding a full time job (30%), moved away from Sydney (25%), student timetable changed (11%), own health, including pregnancy (17%), dissatisfied with job (11%) and other commitments (6%). Rate of pay was never described as inadequate. Attendants may have been reticent to acknowledge a dislike for the work for fear that it may be interpreted as a dislike of the disabled person.

Two service model attendants were dismissed at the request of participants (one for lack of compatibility, one for being unreliable) and one was dismissed at the co-ordinator's instigation (because he was unwilling to act in accordance with her instructions).

All participants reported that the turnover rates experienced were acceptable i.e. rates were not such that they detracted from the advantages of attendant care.

5.4 The Models Compared

The models, as implemented, differed on some key dimensions and were very similar on others.

i) Selection of attendants

Allowance	by participants, occasional assistance from co-ordinator
Service	some by participants alone, other by participants and co-ordinators together (reflecting a difference between the two co-ordinators).

ii) Payment of attendants

Allowance	by participants; timesheets returned for research purposes only
Service	by co-ordinator according to timesheets submitted

iii) Training Attendants

Allowance	by participants, families, other attendants
Service	by participants, families, other attendants and sometimes by the co-ordinator. Orientation provided by the Co-ordinator.

iv) Workers' Compensation Insurance

Allowance	individual policies, relatively expensive
Service	one policy covered all attendants

v) Travel Reimbursement

Allowance	essentially, paid by participants from 'extra' allowance; less costly per hour of work than the service model not paid by all participants even when travel was required.
Service	relatively more expensive than allowance model because of distances travelled and the fact that it was always paid.

vi) Length of Shifts worked

Allowance	slightly greater proportion than the service model of shifts less than one hour and three hours or more, reflecting a greater variability in the way in which assessed hours were used.
Service	95% of shifts were 1, 1.5 or 2 hours.

vii) Employment of relatives as attendants

Allowance	three people employed a relative on a regular basis, two paid a relative as a backup only
Service	one relative employed

viii) Expenditure on items other than attendant care

Allowance	minimal
Service	not possible

ix) Tasks performed by attendants

Allowance	principally personal care but often involved the integration of non personal care tasks; non personal care tasks sometimes done in lieu of personal care provided by a member of the household
Service	restricted at first to personal care only; some integration of other tasks later in pilot

x) Accumulation of unused hours

Allowance	yes
Service	yes

xi) 'Unauthorised' extra hours

Allowance	paid out of own pocket
Service	paid for by pilot in three cases

xii) Attendants Employed

No differences between attendants employed in the two models in terms of age, sex, marital status (slightly more single attendants in allowance model), numbers of dependents, dismissals and resignations, number of shifts and hours per week.

There were differences between attendants employed in the two models in terms of education (more nurses in the service model), previous contact with disabled people (much less in allowance model), how the job was found (more through advertisements in service model), having other jobs (although the proportion in each model having other jobs was similar, the proportion having other full time jobs was greater in the service model), and method of getting to work (more allowance attendants were within walking distance of participant's house).

xiii) Rates of Pay

Allowance	some, but not much variation in rates; rates per hour used for small numbers of attendants were $4 (juniors), $5, $7, $8, $10 (including travel)
Service	all paid Home Care Service award rates.

xix) Use of co-ordinator's time

Allowance	limited to matters related to cheques, insurance policies for participants; help in locating attendants (3 participants on isolated occasions); repeated support and help when household member less available than usual (one participant).
Service	by design, the Co-ordinator was required to involve herself in all aspects of attendant management and participant support.

xx) Participant's satisfaction

Allowance	very satisfied; participants previously dissatisfied with agency-provided service found managing an allowance gave them the level of control they required and presented no insurmountable difficulties. Two previously inexperienced people thought they would feel more secure with agency back up.
Service	very satisfied (the characteristics of this particular service model tried to maximise client control) but half would be just as satisfied to receive the allowance only.

It must be emphasised that it is not necessary to establish 'deficiencies' in either model as a means of justifying the need for the other. It is clear that there has been an expressed need for both. It is also possible that any given individual may prefer and/or need to use a different model at different stages of his life.

6

QUALITY OF LIFE

Research Brief Item C(1)

> "To test claims that an attendant care scheme will facilitate a higher quality of life amongst severely physically handicapped people".

6.1 Introduction

The cost of attendant care is of obvious interest to government. Of at least equal importance, however, is the quality of life attendant care makes possible for people with severe physical disabilities. Quality of life has been variously defined for both groups and individuals, using both objective criteria such as economic productivity, crime rates, average incomes, health indices and standard of housing and more subjective criteria such as perceptions of satisfaction and well being. A "good quality" of life is universally accepted as a desirable goal. Health, education and welfare programs have increasingly included amongst their stated objectives "improvement in the quality of lives" of the participants. There has thus been a growing need, at least since the early 1960's, to be able to measure the quality of life.

6.1.1 Measuring Quality of Life

A plethora of measures had been developed, with differing orientations and purposes. The limitations of each were noted in their application to attendant care in a search for suitable measures for this study. Quality is clearly dependent on many components of varying degrees of importance. The relative importance of specific components may vary in different contexts. Kottke (1982), for example, discussing the quality of life of Americans in general suggests

> ".... as a result of our cultural training, most of us are dissatisfied unless we feel that we not only are interacting members of society, but that we are constructive contributors to Society".

While this component may be of prime importance for a group of healthy, economically secure individuals, it may be of somewhat less concern to a group of cancer patients. Spitzer, Dobson, Hall, Chesterman, Levi, Shepherd, Battista and Catchlove (1981) developed a quality of life index (QL-Index) to assist physicians in assessing the relative benefits and risks of various treatments for serious illness and of supportive programs such as palliative care or hospice service. This index is not claimed to be suitable, however, for measuring or classifying the quality of life of ostensibly healthy people.

Some quality of life researchers have arrived at their finally included set of components, and in some instances the scale values within a component, by tapping community opinion. The Spitzer QL-Index referred to previously was derived in this way. DeJong (1981) developed a scale of living arrangements, one component of quality of life of particular relevance for people with a severe physical disability, by asking a group of people actively involved in the independent living movement to rank seven possible living arrangements from most to least desirable. The resulting scale ranged from "living with spouse, significant other and/or children" to "living in an institution".

Flanagan (1982) empirically identified fifteen factors affecting the quality of life of adult Americans using the critical incident technique, which involved the derivation of a set of fifteen factors from approximately 6,500 critical incidents described by a wide variety of individuals in response to the following two questions:-

. Think of the last time you did something very important to you or had an experience that was especially satisfying to you. What did you do or what happened that was so satisfying to you.

. Think of a recent time you could not do something you very much wanted to do or could not have something you very much wanted to have. What did you want to do or have that you could not do or have?

Flanagan's factors are used as a measure of quality of life by having individuals rate the factors for importance to their own lives and for the extent to which their needs and wants in respect of each factor are being met at a given point in time.

Health status, for which several measures have been developed in recent times, could quite appropriately be included as an important dimension of life quality. The Duke - UNC Health Profile (Parkerson, Gehlbach, Wagner,James, Clapp and Muhlbaier 1981), The Sickness Impact Profile (Gilson, Bergner, Bobbitt and Carter 1979) and the Rand Health Insurance Experiment Profile (Ware, Brook, Davies and Lohr 1978) all health status measures, include physical, social and emotional aspects of life.

There is a high level of convergent validity between the Duke - UNC Profile Self Esteem sub scales and the Tennessee Self Concept

Instrument, with which Green, Pratt and Grigsby (1984) had found, in their study with a group of persons with spinal cord injury, a significant relationship between self concept and perceived independence, provision of one's own transportation, amount of assistance needed and living arrangements.

They also found their sample had higher mean scores for overall self concept scores and for six of the seven sub-scales (four of them significantly higher) than the population norms and only for Physical Self did they score significantly lower than the norm.

6.1.2 Quality of Life and Attendant Care

Only a few studies specifically concerned with attendant care have reported on its impact on the quality of the lives of the disabled users and their families. The first phase of the Personal Care Workers Study (PCWS), Northcote, Victoria (Personal Care Workers Study, 1984) reports that attendant care improved the general morale of all users, reduced perceived dependancy, improved relationships with people closest to them and resulted in improvements to personal organisation and/or domestic situations for most of them. For about half of the users, attendant care also influenced employment for themselves and 'significant others', was crucial to education, had increased community participation and leisure activities and had allowed the significant other to enjoy a break.

A survey of 131 rehabilitation agencies, institutions and programs in the United States conducted by Thornock, Hutchins, Meyer, Kenyon and Williams (1978) revealed that overwhelmingly, attendant care was judged to be extremely or very important in promoting independence, maintaining higher morale, maintaining restored physical condition, decreased hospitalisation and better overall health. It did not necessarily, however increase the likelihood of employment.

Crossroads Care Attendant Schemes in the UK focus directly on the quality of life of the carers, assuming that the disabled person's quality of life will be maximised by living "naturally at home" rather than in an institution. Wood, Runcie and Lindsay (1980) report that the presence of care attendants improves carers' morale and increases their ability to cope with stress.

In a carefully designed evaluation of a new organisation providing community care services to aged and disabled people in three counties in Wisconsin, USA, Seidl, Applebaum, Austin and Mahoney (1983) were unable to find empirical evidence of improved quality of life for the users compared with an institutionalised control group. They could only speculate as to the reasons for their findings, but suggested their experimental and control groups may not have been representative of the same population.

6.2 Selection of measures

A composite of measures was selected for use in this study including both objective and subjective indicators.

6.2.1 The objective indicators are:-

- Living arrangement
- Marital status
- Work status

6.2.1.1 Living arrangement

DeJong's (1981) seven point scale of living arrangements was considered to be less than satisfactory as an indicator of degree of independence on the ground that a specific legal or consanguineous relationship is no guarantee of a particular level of independence. It was neveretheless included (a) because purpose built measures in this area are rare and (b) to assess this evaluator's judgement of it.

	1.	Lives with spouse, "significant other" and/or children.
	2.	Lives alone.
	3.	Lives with friends, unrelated persons and/or siblings.
Decreasing Independence	4.	Lives with parents and with spouse and/or children.
	5.	Lives with relatives such as grandparents, uncles, aunts or adult children.
	6.	Lives with parents or with parents and siblings.
	7.	Lives in an institution.

Figure 6.2: DeJong Scale of Living Arrangements

The scale will be used as a nominal one only.

6.2.1.2 Marital Status

To the extent that the married state and the prevention of marriage breakdown are viewed as "positive" outcomes, marital status will be included as a dimension of quality of life.

6.2.1.3 Work Status

The commonly held assumption that being employed is preferable to being unemployed and that being in open employment is preferable to being in sheltered employment is subject to distortion in the case of people with severe physical disabilities due to work disincentives associated with some government benefits. Disincentives notwithstanding, work status has been included.

6.2.2 The subjective indicators are:

- . Importance and satisfaction ratings of Flanagan's factors
- . Personal and Social subscales of the Duke - UNC Self Esteem Scale.
- . Self report statements by participants and family members.

6.2.2.1 Flanagan's quality of life factors

Flanagan (1982) proposed that an extension of the critical incident technique would be required to identify additional factors sufficiently sensitive for measuring deficiencies and changes in life quality for persons with a disability. As suggested by Flanagan, the following two questions were used to elicit critical incidents from people with levels of disability commensurate with those of the study participants. Respondents for this process were contacted through the Occupational Therapy Department of the Commonwealth Rehabilitation Service's QEII Centre in Sydney.

- . Think of a time in the last week that your disability prevented you from doing something you very much wanted to do. What exactly did you want to do and why couldn't you do it? Can you think of a possible change that would enable you to do what you wanted to do?

- . Think of a time in the last week that you were able to do something important to you that your disability used to prevent you from doing. What exactly did you do and what change made it possible for you to do it?

Many of the incidents described, could be categorised within his existing set of fifteen factors. Only three new factors, all related to independence, were necessary to enable classification of all incidents. It should be stressed that this process was carried out on a very small scale only and not in the large scale exhaustive manner intended by Flanagan.

Physical and material well being

1. Home modified to suit your present physical condition, desirable food, security, transport.
2. Health and personal care.

Relationships with other people

3. relatives
4. sexual
5. having and rearing children
6. close friends

Community and Civic Activities

7. helping others
8. belonging to groups, organisations, clubs

Personal development

9. a course of study, teaching yourself new things
10. understanding yourself (strengths and limitations)
11. Work (paid or voluntary) that is interesting and rewarding
12. Hobbies that allow you to be creative

Recreation

13. Socialising with others
14. Watching sport, films, plays, music, reading
15. Active games and sports (indoor or outdoor)

Independence

16. Make my own decisions about when I do things
17. Run my own household
18. Live with people with whom I choose to live (or alone if I wish)

Figure 6.3: Quality of Life Factors (based on Flanagan)

Each factor is rated on a three point scale of importance (very, moderately and not at all) and on a three point scale of satisfaction with needs being met (very well, moderately, not at all well).

6.2.2.2 Personal and social self esteem measures

Health status measures' sub scales pertaining to Physical Functioning were considered inappropriate for a group all of whom, of necessity, have a permanent severe physical disability. The personal and social self esteem items (17) from the Duke - UNC Profile were selected for use in this study as an indicator of overall morale. Each item is rated on a five point scale from "Describes me exactly" through to "Doesn't describe me at all".

6.2.2.3 Self report

Participants were asked at the outset to describe their activities on a daily basis for a typical week, to pinpoint specific dissatisfactions and to nominate aspects they would like to change for themselves and/or for other family members involved in their care at that time. In subsequent interviews, participants were asked to comment on any changes in their lives that they felt were attributable to attendant care. Other household members, after approximately eighteen months of attendant care, were invited to comment on the amount of personal care they were required to do both then and previously, and on whether attendant care had effected their own independence and quality of life.

6.3 Data Collection

Personal interviews were conducted on three occasions with each participant. Interviews mainly took place in the person's own home at the time they had nominated and as far as possible, in private. The time taken was variable but generally at least an hour was required to complete the interview.

Occasion 1: January/February 1984
For the majority of participants (17) this was immediately prior to commencement of an allowance or service. For the rest there was a delay between the interview and commencing attendant care.

Occasion 2: Approximately ten months after commencement of allowance or service.

Occasion 3: Approximately twenty months after commencement of allowance or service.

In order to complete all three interviews with as many participants as possible, the period of time between commencement of allowance or service and occasion two, and between occasions two and three, was reduced to eight months for four participants who commenced receiving benefits in June 1984 (i.e. four months after the majority).

Commencement was delayed so long for the remaining three participants that only two interviews were possible.

6.4 Results

6.4.1 Objective indicators

6.4.1.1. Living arrangement

Changes on this dimension can be divided into those which were planned for on the basis of availability of attendant care and therefore taking place early in the pilot and those which were unplanned and arose as a result of the making or breaking of a 'significant other' relationship or the death of a parent.

The planned changes include five people moving out of institutions and two people leaving a parental home to live with a 'significant other'. The unplanned changes include three 'significant others' leaving, one person leaving 'significant other', one person getting married and one moving to another relative's home following the death of a parent.

Table 6.1: Participants' living arrangements on occasions 1 and 2

Living Arrangement at Time 1		Living Arrangement at Time 2						
		1	2	3	4	5	6	7
DeJong's Scale of Independence								
1	spouse, "significant other" and/or children	7	-	2	-	-	-	-
2	alone	-	-	-	-	-	-	-
3	friends, unrelated persons and/or siblings	-	-	-	-	-	-	-
4	parents & with spouse and/or children	-	-	-	-	-	-	-
5	relatives, such as grandparents, uncles, aunts or adult children	-	-	-	-	-	-	-
6	parents or with parents and siblings	2	-	-	-	-	8	-
7	in an institution	1	-	3	-	-	1	-

Table 6.2: Participants' living arrangements on occasions 1 and 3

Living Arrangement at Time 1	Living Arrangement at Time 2						
	1	2	3	4	5	6	7
DeJong's Scale of Independence							
1 spouse, "significant other" and/or children	7	-	2	-	-	-	-
2 alone	-	-	-	-	-	-	-
3 friends, unrelated persons and/or	-	-	-	-	-	-	-
4 parents & with spouse and/or children	-	-	-	-	-	-	-
5 relatives such as grandparents, uncles, aunts or adult children	-	-	-	-	-	-	-
6 parents or with parents and siblings	2	-	1	-	-	7	-
7 in an institution	2	-	2	-	-	1	-

A classification of living arrangements in this way misses differences in the perceived degree of control of the disabled person in particular instances. Two people "living with parents" in fact have their parents living with them in their house resulting in a rather different situation. Even in the cases in which the disabled person is living in the parents' home, the levels of perceived independence differ markedly.

The ferment of ideas and change about living options for people with severe physical disabilities taking place in recent years had resulted in major changes in the living arrangements of three participants prior to joining the pilot study. These three changes had been made possible by the availability of some form of paid care (from the Home Care Service of NSW and Sydney Home Nursing Service). Two of these people had left an institution to live in the community, the third had moved from his parents' home to live independently.

Another two participants had previously lived in an institution, one having returned to live with a parent when circumstances changed, the other having married and thus obtained a willing carer.

Table 6.3: Participants' history of institutionalisation and reasons for never having lived in an institution or for having been able to leave an institution

Reason able to avoid institutionalisation or leave an institution		Previously institutionalised for extended period at some time in life	Never lived in an institution
Unpaid care available	Parents	1	8
	Spouse	1	1
Combination paid/unpaid care available	Spouse & HCS	1	1
	Parents & HCS and/or district nursing	0	3
Paid care available	HCS and/or district nursing	1	1
	Attendant Care Pilot Study	5	1
TOTAL		9	15

Three using a combination of parental and paid care prior to joining the pilot became independent of their parents with the full availability of attendant care through the pilot.

Only one of the eight dependent on parental care only prior to joining the pilot has made a change in living arrangements and that was to the home of a married sister on the mother's death. Two are young and in all probability would not yet have left home even if they had not become disabled. At least three people in this group however, have definite plans to move to a home of their own either simply to be independent or to live with a significant other but have been delayed by a variety of factors such as uncertainty about the future availability of attendant care and deference to a hesitance on the part of parents to accept the change. For six people in this group the present age and or health status of their parents is of major concern in that there is a very real risk that they will be unable to continue providing care.

Participants' satisfaction with current living arrangements is discussed in section 6.4.2.

6.4.1.2 Marital Status

Participants living with a 'partner' variously described themselves as legally married, having a defacto relationship or living with a 'friend' who is a significant other. The differences are significant for certain purposes but are not of concern in the present context. The liberty is therefore taken of classifying them all as 'married'.

Table 6.4: Marital status on occasions 1 and 3

	Marital Status at Time 2		
Marital Status at Time 1	single	sep/wid/divorced	'married'
Single	8	0	3
Sep/Wid/Divorced	0	3	1
Married	0	4	5

As Table 6.4 shows, as many people entered into new relationships as there were existing relationships discontinuing.

6.4.1.3 Work Status

Whilst changes in this dimension have occurred during the time of the project, none of the changes could be attributed to attendant care. In one sense, of course, satisfactory personal care arrangements are crucial for the continued participation in any work or study program. The point remains, however, that participants' previously existing personal care arrangements (volunteer, paid or institutional) had enabled many to work or study and the provision of attendant care alone was not sufficient to change the work status of those not previously working or studying.

Table 6.5: Employment or major activity on occasions 1 and 3

	Employment/Major Activity at Time 2							
Employment/Major Activity at Time 1	open		sheltered	voluntary		student	mother	unemployed
	F/T	P/T		F/T	P/T			
Open F/T	6	-	-	-	-	-	-	1
P/T	-	-	-	-	-	-	-	1
Sheltered	-	-	4	-	-	-	-	-
Voluntary F/T	2	-	-	1	-	-	-	-
P/T	-	-	-	-	3	-	-	-
Student	-	-	-	-	1	1	-	-
Mother	-	-	-	-	-	-	1	-
Unemployed	-	1	-	-	-	-	-	2

It cannot be assumed that residents in nursing homes do not work. One nursing home which specialises in providing accommodation for younger people with a severe physical disability, requires its residents to be working or studying in some capacity. The five previously institutionalised pilot participants had all been working (four voluntary, one open employment) and continued in their same positions after leaving the institution. Two of the voluntary workers have since obtained open employment within the same organisation they had done voluntary work for, two have remained as volunteers and the person in open employment resigned.

One person in full time open employment experienced a period of unemployment between jobs. Ten people at the time of their last interview were dissatisfied with their current work status, including all of those doing part time voluntary or paid work, two in sheltered employment, one in full time open employment, two currently unemployed and one person who up until that time had been a full time mother but was then contemplating part time work.

6.4.2. Subjective indicators

6.4.2.1 Ratings of Dimensions of Quality of Life

Group Results
Importance

No single dimension was regarded as very important by all the participants on all three occasions. The majority, however, rated as very important home, health and personal care, relationships with close friends, making own decisions and living with people with whom one chooses to live. The percentage rating a given dimension as very important remained relatively constant across the three occasions except for noticeable increases in the ratings for helping others, hobbies, running own household and living with people with whom one chooses to live. As would be expected individuals' ratings exhibited some variability but changes were almost exclusively between adjacent rating categories. The mean number of changes in rated importance between the first and second occasions was 5.5 and between the second and third, 4.6. Half of the changes between the second and third occasions were however reversals of the changes made previously, resulting in a picture of overall stability.

Table 6.6: Percentages of participants reporting each of the 18 dimensions as very important to their quality of life on three occasions

	Time		
Component	1	2	3
Physical and material well-being			
1 home modified to suit your present physical condition, desirable, food, security, transport	88	96	100
2 health and personal care	96	96	100
Relations with other people			
3 relatives	63	71	65
4 sexual	50	42	45
5 having and rearing children	33	21	20
6 close friends	83	92	90
Social, community and civic activities			
7 helping others	46	63	55
8 belonging to groups, organisations, clubs	13	17	20
Personal development/fulfillment			
9 a course of study, teaching yourself new things	42	50	35
10 understanding yourself (strengths and limitations)	88	92	80
11 work (paid or voluntary) that is interesting & rewarding	79	79	70
12 hobbies that allow you to be creative	13	21	30
Recreation			
13 socialising with others	71	88	75
14 watching sport, films, plays, music, reading	42	63	45
15 active games and sports (indoor or outdoor)	25	13	20
Independence			
16 make my own decisions about when I do things	83	96	85
17 run my own household	58	79	70
18 live with people with whom I choose to live (or alone if I wish)	79	100	95

This group's ratings of importance bear a remarkable resemblance to the ratings Flanagan (1982) obtained from a representative sample of 3000 adult Americans. The percentages are lower for having and rearing children and a sexual relationship but higher for relationships with close friends, understandably lower for active recreation but higher for socialising with others and lower for a course of study/learning new things.

Satisfaction

The levels of dissatisfaction for this group on occasion one are much higher than those reported by Flanagan (1982) for every dimension. The percentage reporting unmet need decreased on the second and third occasions for health and personal care, relationships with relatives and close friends, sexual relationships, a course of study, understanding self, hobbies, active recreation and all three independence dimensions, so that health and personal care, relationships with relatives, understanding self and active recreation had fallen to Flanagan's (1982) levels by the third occasion.

Unmet Needs on very Important Dimensions

The aspects of life of greatest concern to an individual are those rated as being very important but for which unmet needs exist. The mean number of such aspects are reported for each group for three occasions. As four participants were interviewed twice only, the group means with incomplete records excluded are also shown for occasions one and two.

Table 6.7: **Percentages of participants reporting each of the 18 dimensions' needs and wants being moderately or not at all well met. The figures in brackets are the percentages of participants rating an item as important and having unmet needs.**

	Time		
Component	1	2	3
Physical and material well being			
1 home modified to suit your present physical condition, desirable food, security, transport	42 (38)	21 (21)	35 (35)
2 health and personal care	29 (29)	4 (4)	15 (15)
Relations with other people			
3 relatives	50 (25)	33 (21)	15 (10)
4 sexual	71 (42)	63 (42)	60 (40)
5 having and rearing children	54 (18)	54 (4)	50 (25)
6 close friends	54 (50)	25 (21)	30 (25)
Social Community and Civic Activities			
7 helping others	63 (29)	63 (50)	55 (35)
8 belonging to groups, organisations, clubs	75 (29)	46 (8)	75 (30)
Personal development/fulfilment			
9 a course of study, teaching yourself new things	71 (33)	54 (38)	60 (35)
10 understanding yourself (strengths and limitations)	46 (42)	33 (25)	25 (15)
11 work (paid or voluntary) that is interesting and rewarding	50 (33)	42 (38)	50 (45)
12 hobbies that allow you to be creative	88 (13)	58 (33)	65 (30)
Recreation			
13 socialising with others	54 (42)	54 (50)	55 (45)
14 watching sport, films, plays, music,	46 (17)	38 (25)	50 (20)
15 active games & sports (indoor or outdoor)	67 (29)	54 (25)	50 (30)
Independence			
16 make my own decisions about when I do things	50 (42)	46 (42)	30 (20)
17 run my own household	75 (46)	38 (29)	50 (40)
18 live with people with whom I choose to live (or alone if I wish)	54 (46)	29 (29)	35 (30)

Table 6.8: Unmet needs in important areas including only participants interviewed three times

Group		Unmet needs in important areas					
		occasion 1		occasion 2		occasion 3	
	N	$\bar{X}$	sd	$\bar{X}$	sd	$\bar{X}$	sd
Allowance 1	5	5.6	4.4	5.0	2.5	2.8	3.0
Allowance 2	8	5.5	3.2	2.3	1.8	4.8	2.7
Service	7	6.3	5.0	7.0	2.3	7.6	3.4
Total	20	5.8	4.0	4.6	3.1	5.3	3.5

Table 6.9: Unmet needs in important areas including all participants interviewed on each occasion

Group	Unmet needs in important areas								
	occasion 1			occasion 2			occasion 3		
	N	$\bar{X}$	sd	N	$\bar{X}$	sd	N	$\bar{X}$	sd
Allowance 1	7	6.0	3.7	7	4.7	3.1	5	2.8	3.0
Allowance 2	9	5.8	3.1	9	2.9	1.7	8	4.8	2.7
Service	8	7.3	5.3	8	7.8	3.0	7	7.6	3.4
Total	24	6.3	4.0	24	5.0	3.3	20	5.3	3.5

The group results, showing no significant differences, in a small sample project such as this, are of less value than results at the individual level.

Individual Results

Physical and Material Well Being

Initial problems for three people were rectified (access ramps, outside paths) but continue to restrict independence for five others. An owner's decision to sell created a problem for one person in very satisfactory rented accommodation, while living in a granny flat without wheelchair access to the rest of the house lost its desirability for another. Dissatisfaction with prior personal care arrangements was expressed by seven people (four using existing community services, two in institutions and one dependent on aged parents). Only one person was dissatisfied with his paid attendant care during the pilot because the presence of attendants in the house had proved very disturbing for his spouse.

Relationships with Other People

Relationships with relatives remained less than satisfactory for two people but improved for four after the introduction of attendant care.

Absence of satisfactory sexual relationships was indicated by seven people throughout the pilot and by three more during that time. Four people reported improvements in this area.

Four people, all of whom were dissatisfied with their sexual relationships for the whole period were also unhappy about the extent of their relationships with close friends.

Personal Development

Seven of the ten people not satisfied with their understanding of themselves when first interviewed had become so by the third interview.

As discussed previously, there is a high and continuing level of dissatisfaction about employment with those unemployed not necessarily unhappy about it.

Much of the work that is available in both sheltered and open settings (repetitive manufacturing or clerical work) is viewed with distaste both by those who have never had the opportunity to try other types of work and by those previously in much more practical jobs (plumbing, motor mechanic, hairdressing etc). Enthusiasm for employment is also dampened by the relatively low pay and the loss of eligibility for pensioner fringe benefits, particularly the provision of expensive items of equipment through the Program of Aids for Disabled People (PADP) for which a means (and sometimes assets) test applies in NSW at least.

Recreation

Socialising with others is the most valued form of recreation (three quarters rating it as very important) and half the participants continue to experience unmet needs in this area. Other passive and active recreations were important for fewer people (half and quarter of participants respectively) with five people dissatisfied about their active recreation throughout the period.

Independence

Responses to these items highlight the inadequacy of DeJong's (1981) classification of independence of living arrangements. Three of the people who moved out of institutions (one to live with parent,two with unrelated persons) still felt they were not living with people of their own choice or running their own household. One person, living with a spouse for the whole period did not perceive himself as independent in any of these aspects.

6.4.2.2 Self esteem

The consistency of scores over the twenty month period was very high. The correlations between the scores on three occasions are shown in Table 6.10.

Table 6.10: Correlations between self esteem scores on three occasions

	Time 1	Time 2	Time 3
Time 1	1.0		
Time 2	.57	1.0	
Time 3	.82	.74	1.0

Parkerson et al (1981) report temporal stabilities of .74 and .68 for the social and personal sub scales respectively over a period of eight weeks.

The overall mean score was higher than the reported norm and the range was more restricted with the absence of very low scores. Green et al (1984) note the same phenomenon using the Tennessee Self Concept Scale with a group of people with spinal cord injuries.

The mean self esteem scores for each group are reported for each occasion in Table 6.11.

Table 6.11: Mean self esteem scores for each group for three occasions (complete data only)

Group		Self esteem scores					
		occasion 1		occasion 2		occasion 3	
	N	$\bar{X}$	sd	$\bar{X}$	sd	$\bar{X}$	sd
Allowance 1	5	72.4	8.0	77.6	4.7	77.4	5.6
Allowance 2	8	73.4	8.2	76.9	8.6	72.9	10.4
Service	7	72.4	8.5	69.4	11.2	70.4	9.4
Total	20	72.8	8.2	74.5	9.2	73.2	9.1

Table 6.12: Mean self esteem scores for each group for three occasions including all participants interviewed on each occasion

Group	Self esteem scores								
	occasion 1			occasion 2			occasion 3		
	N	$\bar{X}$	sd	N	$\bar{X}$	sd	N	$\bar{X}$	sd
Allowance 1	7	69.3	8.7	7	75.3	6.1	5	77.4	5.6
Allowance 2	9	72.3	8.3	9	75.6	9.0	8	72.9	10.4
Service	8	73.3	8.2	8	68.5	10.7	7	70.4	9.4
Total	24	71.8	8.2	24	73.1	9.2	20	73.2	9.1

Lack of homogeneity of variance together with the inadequacies in sample selection and allocation to groups suggest that no significance should be attached to any apparent differences between the groups.

No relationship was found between self esteem and age, length of time disabled, age at which disabled and whether they had ever lived in an institution. Females had higher self esteem than males and those whose disability was the result of spinal cord injury had lower self esteem than those whose disability had resulted from another cause.

Table 6.13: Mean self esteem scores by sex and cause of disability

Sex	Cause of disability								
	Spinal cord injury			other than spinal cord injury			Total		
	$\bar{X}$	sd	N	$\bar{X}$	sd	N	$\bar{X}$	sd	N
Males	68.5	8.44	11	75.3	3.39	6	70.9	7.70	17
Females	79.5	0.71	2	77.3	6.24	4	78.0	4.97	6
Total	70.2	8.74	13	76.1	4.51	10	72.8	7.67	23

6.4.2.3 Self report

Participants

While the preceding measures were unable to detect significant group improvements in overall quality of life in the more generalised sense, individual rating changes for the dimensions of quality of life showed improvements in a variety of areas for particular individuals. In addition participants were able to report quite specifically the benefits to them of attendant care.

At this point it is useful to consider the impact of attendant care for four groups of participants separated on the basis of previous care arrangements:

1 a) Care had been provided voluntarily for a long time by relatives (two spouses).
  b) Relatively new disability at time pilot commenced (care provided by two parents, one spouse).

2 a) Paid community care.
  b) Paid institutional care.

Only three of those in the paid care group had never used voluntary care provided by relatives.

Essentially the difference between groups 1 and 2 was whether or not the voluntary care system had broken down or not by that stage.

Nine of the eleven participants in group 1 were concerned that their voluntary care arrangements were at risk. The other two, only recently disabled were not thus concerned at that stage.

Since the pilot commenced these fears have turned to reality for four participants:-

- one parent died
- one had major surgery (knee replacements)
- one spouse left
- one parent has developed diabetes

Of the eight people in group 2(a), two had previously lived in institutions due to unavailability of voluntary community care, four had commenced using at least some paid community care in the face of deteriorating ability of parents to cope, one could not have moved to the city to study had paid care not been available and one person had been able to afford paid care until inflation eroded the value of an accident settlement.

Once again the deterioration in parental health since the pilot commenced was very obvious (fractured neck of femur following a fall, arthritis and open heart surgery). It became necessary for one participant to leave a spouse.

The specific improvements in quality of life for group 1 are an enormous relief to know that paid community care is a feasible alternative to institutional care (which previously had loomed large on the horizon as their only option for the future) and for some, experience with attendant care had raised expectations about a degree of independence not previously contemplated.

Group 2(a) had already known that paid community care was a viable alternative to institutional care but had experienced what they perceived to be unnecessary restrictions and lack of flexibility in the forms of care they had been using. For them the specific improvements in quality of life relate to the removal of restriction through the increased individual control possible within the allowance model.

The critical aspects over which control was required are:-

- Permanence of allocated hours ie an individual's hours were not at risk of reduction due to budget cuts, increased numbers of clients or moving to another area.

. Selection of attendants

. What attendants provide assistance with

. When assistance is provided

For all groups the quality of life rests ultimately on having the right to choose where and with whom one will live.

It was perhaps naive to have anticipated improvements in the quality of peoples' lives when often what is required of attendant care is the maintenance of the quality despite changing circumstances of previous carers.

One participant (allowance model) did not remain with the pilot for the full period of time (as explained in section 2). He continued to live in the community getting all the assistance he required from the Home Care Service of NSW.

There were negative outcomes for two participants, each due to quite different circumstances. For one person, whose participation in the pilot had been arranged and encouraged by family members, attendant care was seen as an unwelcome intrusion into what had been perceived by that person (but not by family members) to have been a satisfactory set of arrangements. A subsequent change in attendants improved the acceptability of the scheme but her inability to communicate and her possibly limited intellectual capacity left the organisational responsibilities in the hands of other family members. The second person reporting negative outcomes had applied to participate in the pilot in the hope that it would relieve stress in the household but now feels that attendant care has had a very damaging effect on the marital relationship. His wife had married him knowing she would be his carer and this she had done for many years without pay. To have been excluded from being a paid attendant in this scheme added insult to injury, for she perceived it relegated her to the position of housekeeper. They both agreed that assistance with household tasks that would normally be attended to by the husband would have been of greater benefit than personal care although availability of respite personal care would also be useful.

Individual Personal Studies

There was amongst the participants in the pilot study considerable variation in the nature of impairment, the ensuing disability and other characteristics of income, education, family, gender, ethnicity and individual ability to cope with disability. We have therefore considered illustrative case studies to give understanding of total life situations.

These resumes have been prepared in consultation with and by these participants.

Personal Study AB

I am a male quadriplegic, 40 years of age, single and living at home with my parents and uncle. A surfing accident when I was 18 years old was the cause of my disability. While I lost physical abilities such as the use of my legs, 80% function of my arms and hands, automatic bowel function and bladder control, I did not lose the wish to live my life as an independent person who could live and work in the general community.

There were frustrations as I adjusted to a reduction of access, the realisation that I would be in a wheelchair for the rest of my life and the fact that my peers would more easily retain what had been our shared active social life. My family and friends offered encouragement, care and support. While I would not wish to imply any dissatisfaction with the care they were giving it would be true to say that the continued situation of being 'dependent' on family leads to subtle strains. I wanted the opportunity to pursue my natural desire to independence ... this had been denied me as I was restricted by the need for stable care.

Since February 1984 I have been a participant in the Attendant Care Pilot Study, receiving the allowance model. I joined the scheme with the expectation that receiving my care in this way might:

. relieve family stress
. provide an answer to the future as my aging parents would no longer be able to offer the level of assistance needed
. offer to me a level of independence in which I would not need to feel I was the 'object of care'.

I would say that this allowance model has enabled me to

(i) contribute to and be involved with the community
(ii) be employed and maintain an active social life
(iii) be a consumer alongside my fellow man.

The receipt of the allowance each fortnight has enabled me to employ three attendants to provide me with personal care, thereby making it possible for me to remain in the community and achieve a level of independence previously denied me. My allowance covers a total of 22 hours care per week. I find with careful use of the time the attendants are with me, I can "save" some hours for use in other ways to further enable my independence. I am now able to do my own shopping, attend the barber rather than have him visit my home, go for a holiday by myself (with attendant) rather than with my family and generally move more freely about my community.

Three times, including the initial advertisement, I advertised for attendants in the local newspaper and each time, I received at least a dozen applications. More than half these applicants were worthy of consideration for the position. I feel this demonstrates the employment opportunity that attendant care can offer as well as an understanding and acceptance by the general public of the value of such a service.

Throughout the period of this study, I have not experienced any difficulty in administering my allowance. On the contrary, the allowance has enabled me to, at last, take control of my life and my personal care.

As my parents are now both in their late 60's, it's impossible to return to my previous method of care. Without the allowance, I would have only two alternatives.

1. Seek assistance from Home Care
2. Seek accommodation in an institution

Both these options present difficulties.

1 (a) Given the limited budget of Home Care, it is not unreasonsable to assume that I may not receive the hours that I require for my full independence.

(b) I lose freedom of choice and flexibility; I would not be able to "manage" my time to enable further independence.

(c) Apart from myself, people with disabilities in other parts of the country, particularly in other states where there is no Home Care, would be forced to accept the same sorry situation that has been forced on those needing assistance with their daily living since the "dark ages".

2 (a) There is very little, if any, institutional accommodation available that would allow me to retain the quality of life I have achieved and feel is my right.

(b) It would be difficult for me to continue in open employment, as I have for 19 years, while living in an institution.

(c) I would virtually be pulled out of the general community, thereby not only de-humanising me but also reducing considerably my ability to contribute anything back in the way of spending power.

Provision of my allowance (including wages, travel, insurance, administration and assessment costs) would cost approx. $11,920 which compares more than favourably with the cost of providing for such care in an institution.

Typical rosters for organising my care are as follows:

(a) when using the most hours in a single week

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
AM	9 - 11 Attendant 2	6.15-7.15 Attendant 1	6.15-7.15 Attendant 2	6.15-7.15 Attendant 2	6.15-7.15 Attendant 2	9 - 11 Attendant 1	8 - 9 Attendant 1
PM	2.45-5.45 Attendant 2		5.30-7.30 Attendant 2	5-10 Attendant 3	4.00-6.30 Attendant 3		
PM	10.30-11.30 Attendant 1	11-12 Attendant 1	10.30-11.30 Attendant 1	11-12 Attendant 2	10.30-11.30 Attendant 2	11-12 Attendant 1	10.45-11.45 Attendant 1

(b) when using the least hours in a single week

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
AM	8.30-10.30 Attendant 2	6.15-7.15 Attendant 1	5.30-7.30 Attendant 2	6.15-7.15 Attendant 2	6.15-7.15 Attendant 1	8-10 Attendant 2	7-8 Attendant 2
PM	10.39-11.30 Attendant 1	10.30-11.30 Attendant 1	11.30-12.30 Attendant 1	10.30-11.30 Attendant 2	10.30-11.30 Attendant 1	11.30-12.30 Attendant 2	10.45-11.45 Attendant 1

In so far as any scheme would need to make provison for periodic assessment may I suggest that if the assessment procedure, possibly through the existing "rehab" teams in the community already, can look at the level of skills the recipient has, then the method of service can be either the "allowance" or the "service", or perhaps first the service until the recipient has acquired the necessary skills, then the allowance if desired. At all times the wish of the client must be paramount, however, the entire procedure can be subject to regular review through the original teams.

To summarise, it is absolutely imperative that a National Attendant Care Scheme is instituted immediately to enable people with disabilities requiring assistance with their daily living tasks to take their place alongside their fellow man as equal in the terms of quality of life. It is equally imperative that the scheme be funded through the Commonwealth to ensure that the service is equitable throughout the country.

Personal Study BC

"BC" agreed that her experiences could be used to create a personal study, for she wanted to emphasize that Attendant Care relates to 'people' and any scheme introduced should take account of consumer needs and preferences, so that they can control the direction of their own independent lives.

"BC" would best be described as a busy, confident and independent lady who gives considerable time and energy to many organizations and projects, e.g. DARTS (a transport scheme), Helpmates, Northern Support Committee of the Home Care Service, Community Tenancy Scheme for the Hornsby Ku-ring-gai district. The work she does is valued by others and gives her pleasure and satisfaction.

Her disabilities caused some 34 years ago (by polio) necessitate her using a wheelchair for mobility and the services of other people for her personal care but have otherwise done little to diminish her energy, ability or will to participate in the community. The family (particularly her parents) had always supported her pursuit of independence and freedom. They nad to a large extent fitted in with her wishes, respecting her right to direct her own life.

A great deal of apprehension had existed as to what would happen when her parents, particularly her mother would no longer physically be able to provide personal care, or when aging reduced their ability to comprehend and appreciate her needs. It was then a relief that the coincident occurrence of the Attendant Care Pilot Project and the decision to move from her parents' home to share a house with a friend provided an alternative.

The Attendant Care Project was commenced while living at her parents' home and from the beginning there were no difficulties encountered in obtaining suitable attendants. She already felt confident about interviewing and selection because past employment had given her experience in this area. Having decided to move to her own house she felt it was essential to be completely independent with respect to her personal care requirements. While her friend was prepared to offer considerable assistance they wanted to have a routine which would not necessitate her being "dependant". It was already a fact appreciated by her that conflicts could arise when somebody offered or just went ahead and did too much for her. For even if tasks were slowly or awkwardly performed her preference remained to do as much for herself as possible.

The schedule thus developed was;

Monday - Friday

6.45 - 8.45 Getting up, showering, dressing
2.00 - 2.15 Transfer to bed for a rest - plus an hour of voluntary assistance
3.45 - 4.15 Two afternoons - hair washing

The friend with whom she shares the house and expenses gives most of the assistance required during weekends. Neighbours may be called on for transfers in and out of the car and in emergencies e.g. one incident she recalled was once while alone her dinner slid onto the floor and she was able to call on a neighbour for assistance. An attendant who has subsequently become a good friend can also be rung, for example when she is about to drive home, so that this lady can meet her at home to transfer her out of the car.

The allowance provides for 16.5 hours weekly of paid care which by careful and flexible usage (including variations of rates of pay $4.00 - $8.02) has enabled her to save towards times when more hours may be needed, e.g. illness of herself or voluntary carer, holidays, extra appointments etc.

Hours have been kept at this level by using some technical aids and having some modifications made to the house and its furnishings. Until 1984 most costs had been met from her own funds. She has, however, accepted $3000 from the Department of Community Services towards the house alterations.

It is "BC's" opinion that attendant care is vital to disabled persons seeking to live independently, and that ideally both options of service or allowance should continue to be made available.

Personal Study CD

This participant (a 31 year old Male) has integrated household and personal care tasks making for very efficient use of total time required for personal care. During the pilot, when discussing independent community living and the use of attendant care he suggested it offered..." no problems, I don't have to think about it. The allowance has meant that I have been able to choose attendants that I think will be suitable. No one else has to make that decision for me. It has been central to my life to remain as independent as possible. I have recognized that I am restricted (by Muscular Dystrophy) in the physical movements I have but I still sought to attain the independence any other adult seeks. My care as a child and teenager was within a large supportive family. I moved to Sydney in 1983 to undertake an Associate diploma in Rehabilitation Counselling. At that time friends, Home Nursing Services and the Home Care Service provided my personal care.

I came into the pilot programme with the expectation that this scheme could and should work, that it would remove a lot of the uncertainty and restrictions associated with my existing care. It really can be quite terrifying having to rely on a third party to organize attendants - as times of duties can be restrictive, e.g. I was often transferred into bed early in the evening and sometimes inappropriate people were sent. I didn't want to have to go back to living with my family or depending on Home Care Service where so much depended on others recognizing my needs. I shouldn't have to rely on chance in order to have independence.
I have the freedom to organize when my attendants come and the tasks I ask them to complete.

A sample roster would be

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
AM	8-10.30 Attendant 1	8-10.30 Attendant 1	7.30-10 Attendant 2	7.45-9.15 Attendant 3	7.30-10 Attendant 3	8.30-11 Attendant 3	8-10.30 Attendant 3
PM					1-1.30 Attendant 4		
	10.15-11.45 Attendant 2	7.40-9.10 Attendant 2	7.30-9 Attendant 2	9.10-10.40 Attendant 3	11.10-12.40 Attendant 2	9.10-10.40 Attendant 3	7-8.30 Attendant 3

Each attendant works one weekend in three on a regular cycle.

The overall length of the morning shift is governed by my toilet requirements. My attendants' starting and finishing times vary according to the particular engagements I have for the day but I usually require approximately 2.5 hours attendant care, e.g. at 7.30 am on Wednesday my attendant arrives and transfers me from bed to the toilet. At 7.45 they attend to other tasks such as preparing food ready for breakfast, lunch,etc, locating my clothing and doing any necessary ironing. They tidy my desk, prepare my briefcase and papers as required. By having them check on and arrange all the items I am likely to require during the day I then know that if food is left ready, utensils are within reach, appliances switched on, I can manage independently for the remainder of the day. At about 9.15 the attendant would then assist me to complete the tasks of washing, teeth cleaning etc and then transfer me to the bedroom for dressing and grooming. In the evening I only need an attendant for 1.5 hours to tidy up, put items within my reach, assist with my shower and transfer me into bed.

These rosters, which are typical of my pattern during the study, show that it has been possible for me to live independently in a household which I share with another friend. It is possible to integrate duties to efficiently use the attendants' time, such that with an allowance of 28 hours for attendant care, 3 hours of housework provided by the Home Care Service of N.S.W. and about $20 a week subsidy for taxis (Public Transport being inaccesssible) I am able to pursue an active and independent life in the community. While not employed at present I am able to be an active and contributing member of organizations and interests related to disabled people.

My income which is a single Invalid Pension means that I could not possibly afford to purchase paid attendant care privately.

Personal Study DE

Person 'DE' a 25 year old quadriplegic male, although confined to a wheelchair, still wishes to regulate his own life as much as possible and pursue and share his interests of horse racing, music, computers and socializing with friends.

Since a diving accident some six years ago, his care has been organised in several different ways and locations resulting in his having various levels of choice and control over who assists him, when and in what ways. These arrangements have included acute hospital care, two years in a nursing home, which he described as 'a great institution if you're into institutions, but it's rotten compared with freedom', and living within the general community.

He and another young quadriplegic share a house (owned by the latter) and household expenses. For the most part both prefer to also have an able bodied person living with them 'just in case'. This arrangement has not always been problem free, difficulties of becoming too 'dependent' on this person, or hassles 'asking' friends for assistance, have led from time to time to dissatisfactions on both sides and new arrangements having to be made. An earlier pattern of care was that a district nurse provided the majority of the personal care, the Home Care Service assisted with meal preparation and a friend assisted with household and personal care assistance in return for free lodging. This was less than satisfactory as there was little opportunity to have control over the timing of the nurses' visits and household jobs tended to be left undone or not completed to their satisfaction.

The Attendant Care Pilot Project (service model) has offered him more flexibility and control. At the same time the coordinator has been able to assist with selection and appointment of attendants, a feature 'DE' would like to see retained.

At present 'DE's' sister is staying in the house, but is not responsible for any assistance at all, rather the combined rosters of both men's attendants, one group from the Attendant Care Pilot Project (24 hours) and the other from the Home Care Service (28 hours) have been organised to give the following pattern of care:

> Two attendants every morning, one working two hours each day, the other two hours on four mornings and three hours on the rest
>
> One attendant for two hours each evening to prepare and serve the evening meal
>
> One attendant for an hour each night to transfer both men to bed

This system is working to 'DE's' satisfaction as sharing a house means both having company and sharing of expenses. He no longer has to rely on informal arrangements with any other household member, nor is he restricted to times which fit in with an agencies' 'rosters'. This increased flexibility and control in an employer/employee relationship has resulted in the best living arrangement of all the ones he has tried since becoming disabled.

Other Household Members

Written responses were received from seventeen people in relation to eleven participants, commenting on the effect attendant care had had on their lives and on the life of the participant in their household.

The range of people responding is shown in Table 6.14.

Table 6.14: Relationship of other household members providing information

Relationship to Participant	Number of responses
Brother/sister	4
Wife	4
Mother/father	7
Daughter	1
Friend	1
TOTAL	17

Specific improvements mentioned included taking a part time job (1), more time to give to other family members (3), less restricted in times of coming and going (3), less interruption to work and work related activities (4), more time available for study and leisure (7), improved mental and/or physical health (4) and return to a normal lifestyle (4). One mother has been able to stay away for extended periods of time visiting a son and grandchildren. Three people mentioned the relief of not having to do heavy lifting anymore now that age is reducing their ability to do it. Six people mentioned that the participant did not now have to feel a burden on other family members ('burden', 'drain', 'drag', 'nuisance', 'creating difficulties'). Whether a participant had actually experienced such feelings or not, the relatives concerned obviously had entertained such thoughts. Other feelings attributed to participants included benefiting from social contact with attendant (2), less worried (1), more relaxed (3) and more in control of own life (5).

6.5 Summary

During the time attendant care was used

- desired changes in living arrangements occurred for eight people
- undesired changes in living arrangements were prevented for four people (when a previous carer was no longer available)
- 'marriages' were both made and broken
- minimal changes in employment status occurred

- self concept remained stable for both groups and individuals

- the percentage reporting dissatisfaction with health and personal care, relationships with relatives and close friends, sexual relationships, a course of study, understanding self, hobbies, active recreation and independence, decreased

- allowance groups 1 and 2 and the service group did not differ in terms of increase in satisfaction in important areas

- the observed decrease in dissatisfaction for the allowance groups (1 showing a greater decrease than 2) was not statistically significant.

- individual increases in satisfaction were reported by varying small numbers of people for physical and material well-being, relationships with relatives, understanding self, and independence

- people previously dissatisfied with care provided through a service agency found their control over care arrangements greatly increased when in receipt of an allowance

- two people experienced negative outcomes

- other household members living with some participants experienced improvements in their own lives

7

COSTS OF ATTENDANT CARE

Research Brief Item C (2)

> "To test claims that an attendant care scheme will, together with existing community services, provide a less costly system of appropriate support services to severely, handicapped people than existing institutional arrangements".
> Alterations to this item accepted by the Steering Committee (6.12.83) changed the research requirements to:
> "Review existing Australian studies which compare institutional and community costs of care and compare the costs to government of providing institutional and community care for this group of 24 people". (Attendant Care Pilot Study Steering Committee Minutes, 6.12.83).

Severely physically disabled adults in Sydney can choose (or be restricted) to reside in a variety of institutional (e.g. wards in hospitals, nursing homes) and community settings (shared or alone). Within each of these, they may avail themselves of a range of services. The responsibilities for provision and funding of these alternate modes of care are variously divided across Federal, State and Local governments, voluntary organisations, family members and the disabled people themselves. Costs involved with institutional and community care need to be considered in order to give a realistic basis for the proposal to introduce a new scheme.

There has been a move towards increased demand for "paid" personal care services in community settings. Individuals and interest groups have been increasingly lobbying for the provision by government of Attendant Care. A scheme to address the needs of the severely physically disabled would need to implement efficient patterns of expenditure, while being cognizant of the labour intensive nature of personal care and the number of potential users of attendant care services. These issues have been addressed in this study by analysis of the dimensions of this demand in terms of hours of care, (paid and unpaid) used in a community setting (Section 4) and an estimation of the number of severely physically disabled persons with a personal care need (Section 9). This gives a first indication of the demand that may be placed on attendant care services.

It was our objective to consider the claims that Attendant Care would, together with existing community services provide a less costly system of appropriate support services to severely physically disabled people than existing institutional arrangements.

It is recognised that the measurement and assessment of comparative costs is a complex task. We would agree with Bennett and Wallace (1983) when they note that costs are by no means the only relevant factor affecting the balance of care or decisions about levels of support which should be provided. Some comparative cost studies have attempted to deal with this by assuming that the benefits of the alternatives are identical and purporting to rank them only in terms of cost. The problem of measuring and comparing the benefits still remains and it can only be partly resolved by policy makers making subjective assessments of the benefits involved. A more systematic attempt has been made to examine the benefits of the Attendant Care Scheme in Section 6.

7.1.1 Literature relating to costs of care

Considerable controversy exists in the literature relating to home care costs, mainly concerning which costs are to be included. Several studies have been undertaken both overseas and in Australia which have compared costs of care at home, in hospitals, nursing homes, hostels and group dwellings. Examples are Economist Intelligence Unit (1974), Skellie, Mobley and Coan(1982), Commonwealth Department of Health (CDH) (1980), Philips (1981) and Australian Housing Research (AHRC) (1982). Many of these studies have regarded the various different modes of care as alternatives and attempted to take account of the costs involved in these settings when an adequate level of care was provided. Efforts were made in some cases to measure as fully as possible the economic concept of opportunity cost. The difficulty of applying a monetary value to increased or reduced quality of life experienced by clients or their carers thwarted some of these efforts. To date very few studies have attempted to measure and value both the benefits and costs of home care.

The importance of considering a comprehensive measure of cost is highlighted by the suggestion that some early arguments which asserted that home care was considerably cheaper than institutional alternatives, may have been overstated. Such arguments have subsequently been countered by the assertion that home care options may have been reported as less costly because they omitted a number of items included in the cost of institutional care such as food and home running costs (Philips 1982).

If total costs are being compared then they should be as comprehensive as possible and include all resource costs or if not, exclude the same ones from each alternative under consideration. We have relied on three studies as a basis for the methodology used here: CDH (1980), Philips (1981) and AHRC (1982). These have taken into account methodological considerations, as well as more detailed analysis of the characteristics of the users of services. All of these analyses made an effort to identify all relevant costs although not all studies actually measured and assessed them all.These studies recognised that, in the context of the provision of long term care for the aged and disabled, cost is affected by at least four interrelated factors:

> "The method of measuring the cost, the quality of the care being provided, the level of disability of the patient and, in the case of home care the household arrangements of the patient." CDH (1980, p4).

To these four factors might also be added the efficiency with which the services are provided, this factor being particularly important when considering both institutional and home care (where a lot of transport is involved in moving the clients and the service providers).

Perhaps the most important factor is the comprehensiveness of the measure of the cost of care.

CDH's (1980) detailed study took into account two factors when comparing costs; for whom the costs are being compared and how costs are defined. The concern with home care costs was how these costs were defined in regard to cost of services, or the resource cost of home care, i.e. the services plus the costs of accommodation, food, heating and fuel. He found that if the measure used was the "cost of home services", the cost of home care was always much less than hospital care and except for those patients requiring extremely intensive levels of services, less than the cost of nursing home care. Using his "resource cost of home care" it was found that the home care cost was much less than the cost of hospital care, less than nursing home care for virtually all patients who lived with family and whose level of disability would necessitate nursing home care if home care was not available and for those who lived alone the cost of home care could be greater than the cost of ordinary (but not extensive) nursing home care unless this accommodation was a boarding house or bed sitter.

The methods used in this study are not always consistent in what was included in the packages of services in the different modes of care being costed and compared.

Philips (1981) in a detailed evaluation attempted to overcome some of these problems by making the packages compared as similar as possible and including in home care packages the cost (imputed) of unpaid care services often provided by relatives and friends. Philips' (1981) results indicate that " when the cost of packages of home care were compared with institutional care, it was found that for people living at home alone, and also with a relative, in a medium sized dwelling unit, average service costs were very similar to those for patients in nursing homes. This contrasts strongly with the results of the CDH (1980) study which found that such people would have to be occupying much larger housing units before the costs of home care approximated the cost of ordinary nursing home care." p. 102.

This difference can largely be accounted for by Philips' (1981) inclusion of an imputed cost of informal care provided by family and friends, (which was not included in the CDH (1980) or other earlier studies). Philips (1981) did not however attempt to estimate the offsetting psychic benefits which relatives or friends may receive in providing such care and assistance.

Meaningful cost comparisons can only be made for individuals or homogeneous groups of people. The methodology developed in the AHRC (1982) study allows for such comparisons to be made in the light of how many units of service each person would wish to purchase. Their aim was to compare the costs of different methods of providing services. The comprehensive nature of services provided in an institutional setting was accounted for, in particular the 'hotel like' services provided. Thus they included in their costing all elements; food, lighting, heating and medical services. In this way reasonably valid cost comparisons could be made based on the provision of similar services and acknowledgement that cash costs were not necessarily coincident with resource costs.

Three measures were listed which are often used in estimating the costs of care in an institutional setting:

"Estimation of average operating costs by dividing total expenditure by the number of patient days provided in a given period".

"Estimation of total operating costs per patient day exclusive of outpatient costs".

"Estimation of total operating plus capital costs per patient day exclusive of outpatient costs" (AHRC, 1982, p60).

They note that these estimations include medical,paramedical care, meals, accommodation, heating, light and entertainment. When all resource inputs are treated as 'paid' i.e. no voluntary labour,the "resource costs" respresent the costs of resources "given up" by society. Any studies which have compared the cost of institutional care on a resource basis with cost of home care on its cash cost basis have unfairly weighted the comparison in favour of home care.

The study's concern with addressing comparisons of the cost of like services necessarily led to a comprehensive measure which included all elements and services. Included in their methodology were;

(i) capital costs, which were converted to an equivalent annual cost,
(ii) operating costs, these being the recurrent costs of accommodation, meals, medical and paramedical services, personal care, house care, training and administration, such costs were referred to as unit costs - noting their attachment to particular services each time they were performed, e.g. cost or to a unit of time e.g. cost per hour of house care.

Using their approach of estimating, or considering actual frequencies of service and relevent unit costs, it is possible to calculate the cost of services used by any individual. This method is very similar to the method of compiling packages of services for costing as developed by Philips (1981) and other studies.

Using a cost assessment model AHRC (1982) analysed their data and developed a cost comparison table, which showed relative costs between the alternatives on a $ per patient day basis (see Appendix H).

While several other Australian studies have attempted to explore the methodological issues, Bennett and Wallace (1980,1983), Chetwynd (1983), few have developed cost estimates for particular services for the aged and disabled and there have been few which have compiled comprehensive costs for home and community care as well as institutional care (Owen, 1982).

Some of these studies have been summarised elsewhere , Philips (1981) and also an excellent review of recent British research and methods is to be found in Knapp (1984).

The approach adopted in our study builds on these methods, particularly the studies of AHRC (1982), CDH (1980) and Philips (1981). The important point of departure, however, are the primary research questions: Why do we want to know the cost? Whose cost is to be calculated?

7.1.2. Approach taken to Australian Attendant Care Pilot Project Costs

It is important to define the boundaries of any cost evaluation exercise because measuring cost and benefit is itself a costly activity and it must also be assessed in terms of the value expected to be gained from the cost information obtained. The previous studies attempted to measure and compare differences in the total cost to society of existing alternative modes of care. Little attention was given in most of these studies to the question of who bears the cost and to differences in the structure or shares of cost.

When evaluating a new mode of care such as the pilot Attendant Care Scheme it becomes almost as important to know the answer to the question: less costly for whom ? Is it for society as a whole or only for Government, or family or the disabled persons themselves ?

With a relatively small sample of 24 volunteers the approach was taken that, rather than attempting to measure and value all the relevant costs to society it might be more illuminating to attempt to calculate only the costs to government of the two approaches to providing personal care being evaluated in the Pilot Study and compare these with costs of some types of institutional care. This will mean that elements of other parts of the total cost will be identified but not necessarily quantified or valued.

It is considered that such an approach can be justified in the present context where consumers are pressing for more of both types of options to be made available i.e community care and institutional services, rather than the total replacement of one by the other.

The second justification is that given the considerable effort and expense devoted to the task of quantifying at least some of the benefits of each alternative, the cost of expending limited project resources on the extension of the costing component might not have been worth the additional knowledge gained (Cost Consultant's Recommendation 1985).

This study makes no claim or pretence of measuring all elements of total social cost and this should be considered particularly when use is made of the findings of the study. However the process of estimating the cost to Government involves virtually all the major components of cost except for the unpaid voluntary care provided formally through agencies and informally by family and friends. Because of the importance of this component in the provision of attendant care services in the community it was decided to estimate and include the actual amounts of care received by the sample clients even though we have not placed a monetary value on such care (see below for further discussion of this point).

This study will focus on the share of the total social cost of the alternatives under consideration which is met by government expenditure, by considering the level of subsidy and expenditure on institutional care and the extent to which similar funding to the individual could meet the personal care needs of severely physically disabled people.

Our brief for this study was to compare the costs of an attendant care scheme (together with existing community services) with the cost of existing institutional arrangements. Existing institutional arrangements for those with severe physical disabilities comprise only nursing homes. The level of subsidy available for organisations providing hostel accommodation for the non-aged disabled (available for the non-aged since 1974), a total of $55 per week per approved resident (Hostel Care Subsidy of $11 per week plus Personal Care Subsidy of $44 per week), is not a viable option for those with severe physical disabilities. Residents requiring approximately half an hour of personal care per day meet the eligibility requirements for payment of the Personal Care Subsidy. The Attendant Care Pilot Project was targeted at people requiring at least two hours and up to four hours per day of personal care assistance. It was not considered necessary to include a comparison with presently non existent forms of institutional care (such as, for example, hostels for which a higher level of subsidy could be payable) nor was it sensible to include a comparison with existing community care options. The latter are, however, addressed, particularly in terms of their inadequacy as they currently operate to meet the attendant care needs of the severely physically disabled, in Section 8 (but not in terms of comparative costs).

The main aim of this costing study, therefore, was to estimate the cost to government, at all levels, of providing the services necessary to enable severely physically disabled people to live in the community with the Attendant Care Scheme and to compare such costs with those incurred in providing nursing home accommodation for this group.

The participants in the Attendant Care Pilot study sought to establish and maintain a pattern of care (paid and unpaid) which would permit them integration with the community as a whole. While living in a variety of social and economic circumstances, their emphasis was to maintain, or move towards a life style which maximised the control they had over their own lives.

We have sought to identify the consequences for government funding of transferring these persons from one mode of care to another and to consider whether subsidising care within a nursing home (for which they were all eligible) may be more costly than payment for attendant care services in a community setting.

Consideration was thus given to the extent to which Attendant Care could be considered a practical alternative to the institutional care currently available, given the characteristics and requirements of the pilot study participants, and given that they were assessed by the Department of Community Services' Nursing Home Branch as eligible for admission to subsidized nursing home care if domestic personal care services were to be withdrawn. The severity of their disability would ensure access to subsidised nursing home care (plus use of acute hospital bed if nursing home bed not immediately available) under these circumstances, ie the restricted numbers, in total, of subsidised nursing home beds has not restricted access for this group.

Hostel care, with present levels of hostel and personal care subsidies, do not meet the needs of this group of people, who in terms of the Hostel Personal Care Assessment Standards require "a level of care beyond personal care" (Department of Community Services, 1985b, page 133). The costs of hostel care will not therefore be included in the cost comparisons.

For the duration of the study provision of personal care assistance was made either by a service model, or direct allowance provision for the pilot group participants to determine and purchase services which met their personal care needs.

The costs involved in providing attendant care are only a picture of those costs at a particular point in time. We would acknowledge that long term care would involve a complex of costs and may be affected by, for example, changes in household arrangements or health status of the disabled person or their relatives over time. Longitudinal monitoring of an Attendant Care Scheme, if and when introduced will provide information about these longer term impacts.

In measuring and comparing the costs which would be expected to be incurred in the alternatives of institutional and home care we have used the concept of government expenditure as the primary indicator of cost to government. It is important to point out that cost in the economist's sense of something (benefits) foregone to obtain some desired object is not strictly identical with the money expenditure made to obtain the object. Resource cost is used to refer to what is paid to obtain say a week of nursing home care and accommodation. Under many circumstances the price paid (expenditure) may be a reasonably accurate indicator of the cost of the things which are given up because a market price system exists. Government expenditure is often only a poor indicator of what is given up, the ultimate cost to taxpayers to enable the revenue to be used for purchasing things like attendant care or nursing home care rather than others such as education or private consumer goods.

Table 7.1 Classification of the Costs of Attendant Care Project

	Direct Care Agency Attendant Care Program	Other Agencies	Clients and Others
Directly by	Expenditure on v .services of attendants v .coordinator/admin v .assessment v .insurance v .travel/attendants v .office expenses	Expenditure by .Housing Commission .Subsidies and expenditure on v home nursing care, v hospital services v and respite nursing home care	Expenditure by clients on e .housing and modifications e .equipment e .food e .house care e .travel and entertainment
Indirectly	. Expenditure not specifically related to clients as a group	.Expenditure not specifically related to clients as a group, on social workers, occupational therapists etc.	e .lost work and leisure opportunities of relatives .strain on relatives

Modified from Knapp M.J. The Economics of Social Care Macmillan, London, 1984 p123.

Costs fall on the agency directly responsible for care, in this case the Attendant Care Project and thus the Commonwealth Government, on other agencies such as the Housing Commission, the local health services and the clients' relatives, friends and neighbours. These costs are incurred either directly or indirectly. Among the direct costs would be those immediately and readily attributable to clients or groups of clients through the relevant government or voluntary agencies and their accounts. It is feasible to obtain without too much difficulty the average weekly costs of the Attendant Care Project and of the alternative residential (nursing home) care for disabled people. It is much less easy to obtain estimates of the indirect costs such as those associated with social workers or occasional visits by health workers or those incurred by the clients' relatives. Within this framework we may also distinguish costs of three basic kinds (1)current operating costs which may include (2)living costs of the clients, labour costs and (3)capital costs.

The costs which are to be estimated, valued and included in the cost to government in this study are indicated with a 'v' in Table 7.1. Those considered and estimated but not valued or included are indicated with an 'e'. Those excluded are the remainder.

7.2 Costs of Attendant Care under the Pilot Scheme

In this pilot study Attendant Care was largely personal care, but did include some additional tasks such as meal preparation, personal washing/ironing, and shopping, when necessary.

Living in the community was facilitated by one of two models;

1. Service Model plus social network support(for some including family).
2. Allowance Model, plus social network support (for some including family).

Costs were developed separately for each model. The component costs which need to be included in the direct cost of attendant care are the costs of:-

- hours of paid attendant care used
- administration of the scheme
- assessment of clients
- workers' compensation insurance
- travel reimbursement for attendants

The allocation of paid attendant hours was determined after assessment by the occupational therapist, who took into account the functional level of each individual, life styles, expectations of independence, the informal 'free' network available to each participant and the extent to which its usage was desired by the disabled person, family and friends.

The Attendant Care Pilot participants thus initially decided in consultation with the project's occupational therapist, the number of hours of Attendant Care they would need over and above that which they chose to receive from family/unpaid household members. The hours of

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care allocated, ranged from 14 to 28 and are presented in detail in Table 7.2. The attendant wage cost for these hours varied during the pilot period from $7.51 per hour in January, 1984 to $8.02 per hour in August 1985.

Table 7.2: Initial allocation of attendant care hours

Model	Participant	Barthel (derived from Colville)	Household arrangements (living with)	Hours allocated
Service	A	36	parents & son	21*
	B	36	parents	21
	C	52	sharing	16#
	D	51	mother	21*
	E	51	wife and adult children	15.5#
	F	42	wife, mother in law, adult step son	17.5
	G	20	parents and sibling	18.0
	H	32	with friends, 1 disabled + fiancee	19.5#
Allowance	I	35	parents	22
	J	25	mother & brother	14
	K	15	parents	16#
	L	32	wife & children	21
	M	26	parents 2 B&S	17.5*
	N	35	friend	19.5#*
	O	27	wife & children	14
Allowance	P	32	mother	19.5
	Q	25	spouse	23
	R	35	parents	21#
	S	58	parents	14*#
	T	25	spouse	18*#
	U	37	spouse & child, mother	20.5*#
	V	37	friend	28
	W	56	friend	28
	X	47	spouse	24* **

* Indicates there have been subsequent changes to allocated hours.
# Indicates there have been changes in household arrangements.
**Indicates changes in functional status.

Some adjustments to allocated hours were made during the pilot, in response to participants' requests for reassessment (for details see Section 4).

Table 7.3: Adjustments to allocated hours during pilot

Person	Functional Assessment Barthel	Change in Household Arrangements	Hours Allocated
T	25	with friends	18 → 22 → 25.5 → 27
X	32	no change	24 → 26 → 36 → 42
H	32	disabled friend	19.5 → 20.5 → 24
A	36	no change	21 → 23
D	51	no change	21 → 18
M	26	no change	17.5 → 19.5
N	35	with spouse	19.5 → 21
S	58	with spouse	14 → 16.5
U	37	with child	20.5 → 25.5

Separate rates for administration costs have been developed for the service and allowance models because there was a difference in requirements and emphasis of the co-ordinator's role in the two models. Duties of the coordinator included, organising payments of attendant's wages, negotiating terms and payments of most insurance policies, receipt and monitoring time sheets of service model attendants. Additional services were made available to the service model participants by way of assistance with staff recruitment, selection and training, as required.

It should be noted that the level of experience and independence of the participants in the pilot study may not reflect the needs of all potential users of Attendant Care. The future role of scheme coordinator may be related to the need for, and extent and location of Independent Living Training Programmes which would need to be made available.

Included in the calculation are both direct and indirect costs as follows;

Administration Costs - Financial Year 1984/85

Wages - co-ordinator (part time)	16,457
- book keepers (part time)	2,238
Travel - administrator	729
Stationery, postage, bank charges	715
Telephone	358
Meetings	422
Secretarial Services	100
Office Rental	1,770
Miscellaneous	100
TOTAL	$22,889

The total administration cost was divided by the total number of hours of service administered, service model hours having arbitrarily been weighted by a factor of 2 to take account of the additional requirement for coordinator's time in that model. The resulting administration cost per hour of care was $1.49 for the service model and $0.72 for the allowance model.

In considering actual administrative costs for the pilot it is as well to be aware of the non-routine tasks covered by the co-ordinator. Liaison with other projects and services, involvement with the participants' concerns with post scheme personal care arrangements, which were necessary in a demonstration pilot scheme but would not be part of an ongoing service. There is also uncertainty concerning the marginal costs for any additional hours of service the administration could have managed at no extra cost had the sample been larger. It was not possible for the Co-ordinator to supply accurate information about the proportion of her time devoted to each model, hence the somewhat arbitary double weighting given to service model hours in the above calculations. It is considered that this weighting was conservative i.e. was likely to have overestimated allowance and underestimated service model administration costs.

Costs of assessment

The occupational therapist offered the following as a summary of her duties in a twelve month period during the pilot, and as an indication of requirements for any ongoing scheme.

	Hours
Routine reassessment (24 at 3 hours every 6 months)	144
Requests for reassessment of hours (6 at 3 hours)	18
Assistance with home modifications, information and services (4 at 12 hours)	48
Assistance with information and obtaining of special equipment (6 at 4 hours)	24
Ongoing support for independent living (3 at 8 hours)	24
TOTAL	258

The part time salary and cost to the department employing the occupational therapist were estimated at $0.18 per hour of care.

Cost of insurance/workers compensation

The employer/employee relationship of Attendant Care necessitated that participants purchase workers compensation cover.

Service model participants were covered by one overall policy which was negotiated by the co-ordinator with the G.I.O. As is usual in this type of policy, the premium was linked to the value of salary, not the number of employees or their hours worked.

On the basis of estimated earnings of $67,000, the twelve month policy for 1984/85 cost $665, giving a cost per hour of care of $0.10 for the service model.

The participants in the allowance model were able to choose between purchasing policies negotiated with companies of choice or use the services of the co-ordinator to assist in purchase and continued payment of cover from the G.I.O. Most participants opted for the latter method although their policies were purchased on an individual basis.

The premiums ranged from $244.60 to $656.73 per annum, again based on estimated earnings (including travel reimbursements), giving a cost per hour of care ranging from $0.24 to $0.60 for the allowance model.

Cost of Travel Reimbursement for Attendants

Following a change in administration policy (made by the management committee), the flat rate of $1.00 per hour worked initially paid to allowance participants for travel reimbursement was replaced (March 1984) with the per kilometre rate being paid to service model attendants, a reimbursement similar to, but without the same boundary restrictions as the method used by the Home Care Service of NSW. The amount paid to each participant for the travel component was, from March 1984 intended to be subject to variation with staff changes. Travel amounts in the service model were adjusted in relation to time and travel sheets submitted by attendants. The travel amounts to allowance model participants have however remained static for the majority of allowance participants throughout the pilot period and the total paid remained as calculated on the basis of kilometres actually travelled by the particular attendants employed as at March 1984.

Table 7.4: Comparison of the amounts received and paid out for travel by allowance participants

Model	Allocated hours per fortnight August 85	Travel component in fortnightly cheque		Travel paid out to attendants August 85	Difference
Allowance 1		Total	per hour	per hour	per hour
I	44	$49.68	$1.12	$0.98	$-0.14
J	28	25.76	0.92	0.96	+0.04
K	32	25.76	0.80	0.35	-0.45
L	42	NIL	NIL	NIL	NIL
M	39	27.60	0.70	0.69	-0.01
N	39	88.32#	2.27	Paid hourly rate of $10	-0.29
O	28	12.88	0.46	0.49	+0.03
Allowance 2					
Q	46	45.88	0.99	1.15	+0.16
R	42	179.40	4.27	3.20	-1.07
S	33	58.58	1.78	.90	-0.88
T	54	27.36	0.50	.34	-0.16
U	51	164.68	3.22	2.16	-1.06
V	56	41.41	0.73	.43	-0.30
W	56	wk 1 42.78*	0.76		
		wk 2 52.70	0.94	.02	-0.80
		wk 3 42.78	0.76		
X	84	NIL	NIL	NIL	NIL

# paid higher total hourly rate to Attendants
* was rotating roster of staff

7.2.1 Costs of service model

Allocated hours of attendant care plus travel, administrative, assessment and insurance costs formed the upper limit of service model costs, such that at August 1985 cost per week was the sum of:-

- allocated hours at $8.02 p.h.
- $0.10 p.h. insurance
- $1.49 p.h. administration
- $0.18 p.h. assessment
- travel at 23c per kilometre.

The maximum cost per individual service participant, assuming all hours were used, would be as indicated in Table 7.5.

Table 7.5: Service Model Costs - possible maximum if all hours allocated were used, August 1985

Person	Cost per hour $	Assessed hrs	Cost per week $	Cost per annum $
A	12.17	23	279.91	14,555
B	12.14	21	254.94	13,257
C	12.75	16	204.00	10,608
D	11.87	18	213.66	11,110
E	10.90	15.5	168.95	8,785
F	11.95	17.5	209.12	10,874
G	13.20	18	237.60	12,355
H	11.26	20.5	230.83	12,003
Mean	12.03	18.7	224.88	11,694

The service model reimburses for actual services performed, the variation in money spent or saved reflects changes in patterns of usage. Monies 'saved' reduced the moneys spent on wages and travel for the service model in a twelve month period from $93,551, by $3,436 to $90,115. The 'savings' for each individual for the financial year 1984/85 are shown in Table 7.6.

Table 7.6: Service Model wages and travel - actual expenditure for financial year 1984/85

	Cost per hour $	Assessed hrs/week	Av hour/wk used	Diff/ week	Weekly cost $	Annual savings
A	10.40	23	23.92	+0.92	248.77	- 497.54
B	10.37	21	21.63	+0.63	224.30	- 339.72
C	10.98	16	14.82	-1.18	162.72	+ 673.73
D	10.10	18	15.88	-2.12	160.38	+1,113.42
E	9.13	15.5	14.02	-1.48	128.00	+ 702.64
F	10.18	17.5	13.43	-4.07	136.71	+2,154.50
G	11.43	18	19.11	+1.11	218.42	- 659.74
H	9.49	20.5	19.91	-0.59	188.94	+ 291.15

7.2.2 Costs of allowance model

Allowances received by participants at August 1985 ranged from $8.02 to $12.43 per hour, (to enable them to pay the wages and travel reimbursement to their attendants).

Table 7.7: Allowances actually being paid as at August 1985

Group/ Person	Allocated hours per week	Wage per week	Travel per week	Total per week	Rate per hour	Rate per annum
		$	$	$	$	$
Allowance 1						
I	22	176.44	24.84	201.28	9.14	10,467
J	14	112.28	12.88	125.16	8.93	6,508
K	16	128.32	12.88	141.20	8.82	7,342
L	21	168.42	nil	168.42	8.02	8,758
M	19.5	156.39	13.80	170.19	8.72	8,850
N	19.5	156.39	44.16	200.55	10.28	10,428
O	14	112.28	6.44	118.72	8.47	6,173
Allowance 2						
Q	23	185.31	22.94	208.20	9.05	10,829
R	21	169.27	89.70	258.97	12.33	13,466
S	16.5	132.33	29.29	161.62	9.79	8,404
T	27	216.54	13.68	230.22	8.52	11,960
U	25.5	204.51	82.34	286.85	11.24	14,916
V	28	224.56	20.70	245.26	8.75	12,754
W	28	224.56	21.39	259.00*	8.89	13,001
			26.35	251.00		
			21.39	245.95		
X	42	336.84	nil	336.84	8.02	17,515

* This participant used a rotating roster.

When administrative costs of $0.72 Assessment costs $0.18 and insurance (various ranging from $0.24 to $0.60) costs are included the total hourly rate for Allowance model participants ranges from $8.92 to $13.83.

Table 7.8: Total cost of allowances as at August 1985

Model	Person	Allocated hours p.w.	Hourly rate	Weekly cost	Total per annum
			$	$	$
Allowance 1	I	22	10.42	229.24	11,920
	J	14	10.19	142.66	7,418
	K	16	10.16	162.56	8,453
	L	21	9.17	192.57	10,014
	M	19.5	9.93	193.64	10,069
	N	21	10.45	219.45	11,411
	O	14	9.70	135.80	7,062
Allowance 2	Q	23	10.35	238.05	12,379
	R	21	13.83	290.43	15,102
	S	16.5	11.08	182.82	9,507
	T	27	9.39	253.53	13,184
	U	25	12.64	316.00	16,432
	V	28	9.96	278.88	14,502
	W	28	10.09	282.52	14,691
	X	42	8.92	374.64	19,481

It should be noted that in contrast to the Service Model, there is no reduction in cost to the project when fewer hours of paid care are actually used by allowance participants. The actual hours paid for by allowance participants are shown in Table 7.9.

Table 7.9: Hours of care actually paid for by allowance participants (over 6 month period July 85 to Jan 86)

Model	Person	Allocated Hours per week	Actual hours used average per week	Unused hours average per week
Allowance 1	I	22	20.3	1.7
	J	14	12.3	1.7
	K	16	11.3	4.7
	L	21	19.2	1.8
	M	19.5	18.0	1.5
	N	21	21.5	-0.5
	O	14	12.9	1.1
Allowance 2	Q	23	19.9	3.1
	R	21	17.9	3.1
	S	16.5	15.7	0.8
	T	27	25.7	1.3
	U	25	24.4	0.6
	V	28	25.4	2.6
	W	28	29.5	-1.5
	X	42	40.9	1.1

Much, but not all of the variation in assessed hours (some was due to differences in functional level) was due to variation in the amount of unpaid assistance individuals planned to use. In practice, the actual amounts of unpaid assistance used, together with intermittent changes to routine and variations in rates of pay offered, have acted to keep expenditure on wages to registered attendants below the allowances received for 13 of the 15 people receiving allowances. As discussed in Section 5.1.4, amounts included in allowances for travel reimbursement to attendants were not altered as requirements changed and therefore resulted in "overpayments" to some participants.

Table 7.9A: Estimated amounts not expended by Allowance Model Participants on Payments to Attendants (Wages and Travel) over the six month period July '85 to January '86

Person	Allowance not spent on Payments to Attendants average/week		
	* Wages Component $	Travel Component $	Total $
I	13.60	3.08	16.68
J	13.60	-0.56	13.04
K	37.60	7.20	44.80
L	14.40	0	14.40
M	12.00	0.20	12.20
N	-4.00	5.66	1.66
O	8.80	-0.42	8.38
Q	24.80	-3.68	21.12
R	24.80	22.47	47.27
S	6.40	14.52	20.92
T	10.40	4.32	14.72
U	4.80	27.03	31.83
V	20.80	8.40	29.20
W	-12.00	22.40	10.40
X	8.80	0	8.80

* based on average hourly wage rate of $8.00/hour

It is important that the reader appreciates the context of such underspending, ie, hours were not subject to reduction on the basis of reassessment (see Section 4.4), underspending may not be regular but due to periods of respite care in a nursing home (Table 7.13), hospitalisation (Table 7.12) or a delay in finding new attendants when others resign. Underutilisation of paid care in the latter situation results in increased use of voluntary care in the interim.

The money thus "saved", with the exception of that used to purchase items other than attendant care (see Section 5.1.9) and that used to pay for respite care in nursing homes (see Table 7.13), has been retained by participants to meet future attendant care needs.

Overpayments of this order, whatever the cause, suggest the need for a reimbursement system.

7.3 Unpaid assistance

Identifying and assessing relevant costs in this area is not easy. It needs to be cautioned that in supplying voluntary care some duties could perhaps be considered non-essential. Further, no assumptions should be made regarding satisfactory work equals pay equation, as time may only be a superficial measure of effort (Moore 1984.) Bennett and Wallace (1983) note that in home based care it is difficult to value the considerable care which may be given by relatives. Valuation of unpaid services may use a method of opportunity costs for estimating the valuation of time and other things given up in providing care. The alternatives they suggest for valuing such time include:

. the forgone earnings of the providers of care if they would otherwise be in paid employment
. the cost of providing a paid attendant to replace the unpaid worker
. the compensation the unpaid worker would require to provide similar services if given the choice
. the amount the unpaid worker would willingly pay to some other person to provide similar services.

Although there can be disagreement as to which alternative should be used, this time should not be considered as free, for to do so underestimates the cost of community care.

It would appear that the way in which family/household members contribute their time to personal/attendant care tasks, alters the "cash cost" of attendant care, by lessening the demand for actual hours required by a paid, visiting attendant.

In the absence of family/household members completing these tasks it could be hypothesized that an increase of paid personal care hours may be required. It is considered of interest then to tabulate the allocated hours, the actual hours used and estimated voluntary hours used by participants in this study.

Informal Services

Family members

Families had been and continue to be supportive to many participants, both psychologically and materially. Participants indicated that their disability has had considerable impact on their family as well as themselves. The family may have been a nurturing unit which had as part of its role a supporting function towards some participants and often willingly extra responsibilities were assumed. Most participants indicated that changes in roles and relationships should however be considered in the provision of attendant care and felt there should be flexibility in regard to using relatives, or choosing not to for personal care.

Personal care provided by relatives (particularly when stress is considered to be reduced by having some of the care obtained from other sources) should not be equated with poor quality of life, but it is not without cost to the relatives concerned and cannot be assumed to be permanently available or universally desired.

Having a relative does not prevent a person from occupying a nursing home place. It would therefore seem appropriate that government consider substituting paid care for relatives at least in situations where either the disabled person or the relatives do not wish the care to be provided by the relatives.

Table 7.10: Hours of Care Used Paid and Voluntary Per Week

Model	Person	Allocated hours	Actual paid hours used	** Estimated vol. hrs used at home for all assistance *
Service	A	23	23.92	3.5
	B	21	21.63	4.0
	C	16	14.82	4.0
	D	18	15.88	4.75
	E	15.5	14.02	7.0
	F	17.5	13.43	6.5
	G	18	19.11	7.5
	H	20.5	19.91	4.5
Mean		18.7	17.84	5.2
Allowance 1	I	22	20.3	9
	J	14	12.3	6.5
	K	16	11.3	8.0
	L	21	19.2	2.5
	M	19.5	18.0	5.5
	N	21	21.5	2.8
	O	14	12.9	5.5
Mean		18.2	16.5	5.7
Allowance 2	Q	23	19.9	13.0
	R	21	17.9	4.75
	S	16.5	15.7	8.5
	T	27	25.7	5.5
	U	25	24.4	6.0
	V	28	25.4	3.0
	W	28	29.5	.0
	X	42	40.9	10.0
Mean		26.3	24.3	6.3

* includes personal care and pro rata share of household tasks

** assumes all paid attendant hours were actually used

Many tasks completed by unpaid assistants are of short duration. There is no guarantee that the hours listed above are sufficient for any ongoing routine (however as noted previously some voluntary hours may be an oversupply which could in different circumstances be foregone).

There was difficulty in the collection of information relating to voluntary hours, as the participants felt it was difficult to isolate what was being done for them specifically as contrasted with the household in general, or to extract assistance from what were general family or friendly interactions.

We sought nevertheless to gather information of unpaid hours used which were not offset either, by direct contribution to the household by the disabled individuals, or by the attendants employed by them. The data gathered by the occupational therapist during routine reassessment listed in Table 7.3 covered a range of tasks including, personal care, some driving, household tasks, meal preparation and clerical assistance. The hours, paid and voluntary, thus used would indicate the attendant care hours (for personal care and pro rata share of household tasks) needed by each participant in order to live in the community within their current household arrangements.

7.4 Other community care cost elements

Disability has involved all the participants in certain non optional costs. When paid for by the disabled person himself (as noted in Section 4,) difficulties in meeting these costs were reported by participants. This was similarly noted in the study conducted by the National Women's Advisory Council (1983) in which they found such difficulties were compounded by restricted mobility, minority group status in the market place and unsuitability of standard products. As Moore (1984) suggested, disablement may, apart from its impact on the individual reduce their socio-economic status towards a situation which is characterised by a gap between needs and the means to fulfil them. Disability may reduce, or remove entirely the potential to save regularly. Many individuals are frequently forced to use assets in order to survive. Those who have been disabled at a young age may have had little or no opportunity to save. Those who have cared for the dependent disabled may also have incurred costs. Chetwynd (1985) looked at making more explicit some of these so called "hidden" costs and noted that families reported e.g. income opportunities forgone, low gross income. Consideration needs therefore to be given to additional expenditure needed in order to live within a community setting. Government could be required to at least partially meet the following costs, as indeed it already often does, necessarily involved in living in the community for severely physically disabled persons.

Accommodation - assistance to furnish (particularly for those who while living in an institution have had limited opportunity to accumulate savings or possessions).

- Housing modifications - detailed in assessment section.
- electricity and fuel costs.

Equipment - including aids and pharmaceutical supplies.

Transport - as public transport is inaccessible to those in the study group the participants needed to rely heavily on taxi services which provide problems in both reliability and although subsidised, affordability.

Independent Living Training Programmes

- while the pilot group members have not participated in any structured programmes, they have to varying degrees used their family and co-ordinator's and other agencies' time for advice and/or assistance.

Current services in the context of Attendant Care are restricted in scope and availability because of funding limitations and service characteristics. Allocations and responsibilities for those services which are available are undertaken by a variety of Commonwealth, State, Local Government organisations and voluntary bodies. The individual recipient of services often has limited control over the timing or extent of services, as the agency controls the allocation of service - i.e. the disabled person has no guarantee of hours of care to be made available. The non institutional paid care option has until recently been only fully available to those with private means to pay.

Formal Services and participants' usage

Cash Allowances

The existing government cash allowances in this area, the Domiciliary Nursing Care Benefit (DNCB) and the Spouse carer pension are small in size , available only in very special circumstances and paid only to certain categories of relatives of disabled people rather than to the disabled individuals themselves . Eight participants have someone receiving the DNCB on their behalf (one service, seven allowance). The recipients include parents, spouses and a friend.

Many participants indicated their dissatisfaction with this benefit on the grounds that it appeared to be inadequate, inappropriate in that its payment is to an 'other' rather than the disabled person and perceptions of inequities in the approval for payment.

None of the participants were the reason for the payment of a carer pension. The regulations governing both the carer pension and the DNCB, if strictly applied, would prevent their payment in relation to a person with disabilities who is working. The target population for this project, by contrast, was severely physically disabled people in employment, or vocational training or with reasonable employment prospects.

Nursing Services

Several participants had received assistance at some stage prior to using Attendant Care and would likely need to use these services in the absence of paid attendant care.

The Sydney Home Nursing Service is one of the available services in Sydney which offers trained nursing staff who as a supplement to other care attend to the disabled in the individual's home. There is no integration with domestic duties.

The 1984/85 cost of service delivery per visit (at average 30 minutes) was $11.75. This was derived by the service from total costs for all visits A to D categories wherein A - 15 mins, B - 30 mins, C - 45 mins, D - 60 mins. J. Anderson (Pers Comm. 10/85) indicated that visits to quadraplegics usually allocated minimum of 1 hour i.e. $23.50 per hour.

Home Care Service of NSW

As outlined in Section 8 this service has been responsive to needs expressed by individuals and organisations and has developed (to the extent that its budget permitted) extensive personal care services, similar to those used in the Attendant Care Service model.

The 1984/85 cost of service delivery was $12.02. per hour. This was derived from a total expenditure figure (including all Branch and Head Office Costs) being divided by the total number of field hours.

Housekeeping and handyman services offered by the Home Care Service were used in some Attendant Care Pilot households.

Table 7.11: Participants' use of Home Care Service of NSW during pilot to August 1985

Model	Person	No. of hours per week	Services
Service	D	1.5	Housework
	H	2	Meal preparation & housework-shared with other disabled adult.
Allowance	N	3.5	Housework
	W	3.0	Housework
	X	5.0	Housework

Hospitalisation during pilot study to September 1985

A few participants used acute hospital beds during the study period. The reason for the above admissions would, in the participants' view, have made hospitalisation necessary whether living in a Nursing Home or the community, i.e. no greater use of hospital care was considered to be as a result of community living; nor would the nursing care available in nursing homes have reduced the need for acute admissions.

Table 7.12: Participants' use of hospital beds during the study period to August, 1985

Model	Person	Number of admissions	Total number of days
Service	A	1	10
	G	3	56
	H	2	45
Allowance 1	L	1	14
	M	1	24
Allowance 2	R	1	3
	V	1	7

Table 7.13 Short-term Nursing Home Stay During Pilot Study - respite care

Model	Person	Number of admissions	Total Number of days
Service	F	1	14
Allowance 1	K	2	21
Allowance 2	Q	3	30
	X	2	10

In the Service Model no payment was made for Attendant Care during this time, so adjustment was made to total cost. The Allowance Model participants still had their allowances paid; it therefore was included in their total costs.

7.5 Institutional Costs

7.5.1 Existing Institutional Arrangements

For the category of physically disabled people described in Section 3 similar to the participants in the Attendant Care Pilot, there is a real choice of accommodation and services. The range should remain available, for the choice of mode of care should, whenever possible be made in accord with the preferences of the disabled.

There are several institutions in Sydney which offer accommodation and personal care services for younger, physically disabled adults. They vary in size, i.e. number of beds and supplementary or clinical services offered. Policies vary between the organisations which administer these institutions regarding for example, taking up employment or study, or remaining in residence after a cash settlement has been received. All such institutions are classified as nursing homes under either the National Health Act, 1953 or the Nursing Homes Assistance Act, 1974.

All institutions visited and contacted had high occupancy rates and extensive waiting lists. The majority of those on waiting lists were either living in what they considered to be an inappropriate nursing home (for their age and/or disability) or were living in the community with "at risk" care arrangements. Those which had administrative responsibilities suggested that in the event of the introduction of an Attendant Care allowance or service (which offered guaranteed hours to the individual) being made available, many residents would prefer, opt for, and be capable of community living.

The government cash outlay has been noted for each institution. In contrast to community care settings, where the disabled may buy the number of personal care hours they need, institutions, for funding purposes and in regard to state regulations, are required to offer minimum hours of trained and untrained care. These hours provided may or may not be very closely related to the requirements of individual patients.

Nursing homes are currently funded under two separate pieces of legislation involving two distinct schemes; The National Health Act 1953 and Nursing Homes Assistance Act 1974.

The mix of organisations and funding schemes has produced four types of Nursing Homes; these were identified by the Senate Select Committee on Private Hospitals and Nursing Homes Report (1984) as;

- private enterprise participating nursing homes
- charitable and religious participating nursing homes
- charitable and religious deficit financed nursing homes
- government nursing homes

For nursing home benefit purposes an N.H.5. form must be approved. This indicates a continuing need for nursing care by reason of infirmity or illness, disease, incapacity or disability (exceptions being those patients who are covered by Veterans' Affairs or those covered by payment by way of 3rd party or workers' compensation insurance). 'Nursing Care' has not been clearly defined in this context. The distinction between tasks which must be performed by nurses and those which can be performed by unqualified persons, awaits resolution.

Patients in nursing homes are required to contribute towards the cost of their accommodation and care. This is in recognition of costs which would be incurred by a patient in respect of accommodation and food if they were not in residence in a nursing home.

The amount of the minimum patient contribution is prescribed in the regulations to the National Health Act, and is varied whenever the rate of pension or supplementary assistance is varied.

Although new rates applied at June and November 1985 the figures used in this report are as at November 1984 to accord with data collected from other sources.

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Table 7.14: Weekly Rates of Nursing Home Benefits and Statutory Minimum Patient Contribution as at November , 1984

	NSW & ACT $	VIC $	QLD $	S.A. & N.T. $	W.A. $	TAS $
Basic Benefits	233.45	339.50	196.70	273.35	220.85	194.60
Extensive Care Benefits	275.45	381.50	238.70	315.35	262.85	236.60
Min. Patient Contribution	89.25	89.25	89.25	89.25	89.25	89.25

The Senate Select Committee on Private Hospitals and Nursing Homes Report (1985) noted that since nursing homes first became identifiable as a separate entity in 1963 with amendments to the National Health Act 1953 "nursing home benefits have increased substantially both in money levels and as a proportion of total Commonwealth outlays (in real terms)". (p.3)

A consequence of the legislation was that nursing homes emerged as the main publicly supported means of care. This (according to the Senate Report) appears to have been more by default rather than design or "any purposeful policy decision in favour of institutional care over other forms of provision". (p.4)

7.5.2. Costs for selected institutions

Costs for two institutions which specialise in providing care for younger, severely physically disabled adults with levels of severity similar to those of pilot project participants, were collected and used as a basis for the cost estimates used in the comparisons with the cost of community care packages. While this is only a small sample of institutions in the total nursing home industry it is considered reasonable given the small number of such homes catering specially for younger physically disabled people. Seven pilot project participants had lived in one or other of these two nursing homes, as had a number of those in the Home Care Service user sample (Section 8).

ESTABLISHMENT 1

This deficit financed nursing home has 42 residents all in receipt of Extensive Care Benefits. Forty (40) of the residents are functionally quadriplegic and two, functionally paraplegic.

Fees: The patient contribution is $89.25 per week for pensioners and the full fee is $364.70 per week.

Data provided by staff indicated that the direct personal care requirements of residents varied from 20 minutes to 5.5 hours per day. The majority of residents were reported as receiving between 3 and 3.5 hours of personal care per day. With a total of 1040 personal care hours provided for all residents per week, the average allotment in this home was 24.76 hours per week. The care included assisting with medication, dressings, toiletting, showering, dressing transfers and feeding.

Costs for this home were:

	Actual Expenditure 1984/85	Budgeted 1985/86
Commonwealth Subsidy	$ 815,000	$ 986,000
Total	$1,058,000	$1,184,000

Average costs to Commonwealth Government per resident, per week = $373

Actual Care Staff Costs 1984/85

Trained nurses Untrained nurses	$10.60 per hour*

* Separate hours and rates not provided for these categories of staff.

ESTABLISHMENT 2

This nursing home, also deficit funded, has 18 residents, 17 in receipt of Extensive Care Benefit and one in receipt of Ordinary Care Benefit. Seventeen are functionally quadriplegic and one is paraplegic.

Fees: $371.00 per week and the Patient contribution is $95.55, (as at June 1985).

Personal care required by residents varied from less than 30 minutes per day (3.5 hours per week) for one resident (paraplegic) to between 2 and 4 hours per day for the other quadraplegic residents (14-28 hours per week).

	Budgeted Expenditure 1984/85	Budgeted Expenditure 1985/86
Commonwealth Subsidy	$331,490	$308,977
Total	$456,202	$483,860

Average costs to Commonwealth Government per resident, per week = $330

Care Staff Costs 1984/85

Trained nurses	$14.21 per hour
Untrained nurses	$11.37 per hour
Administrator	
Physiotherapist	

7.6 Comparison of Costs to Government of Institutional and Community Care

It will facilitate the comparison between the costs and estimates we have made for various components of the Attendant Care Pilot Scheme and the cost to Government of the equivalent nursing home care if we first bring together each of the two sides of the picture. Table 7.15 summarises the data on use of services and the estimated actual cost per week of these services for the clients of the attendant care scheme. These packages of services used are then compared first on an average basis with the cost of care in the two institutions outlined above.

Table 7.15:

SUMMARY OF USE OF SERVICES AND COSTS BY ATTENDANT CARE PILOT SCHEME CLIENTS

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)		(9)		(10)		(11)	
CLIENT	BARTHEL SCORE	ACCOMM. OCCUPIED NO. IN HOUSEHOLD	NO. BED-ROOMS	ATTENDANT CARE USED		VOLUNTARY UNPAID CARE HRS/WEEK	HOME CARE		NURSING HOME RESPITE		ACUTE HOSPITAL		DNCB $/WEEK	TOTAL COST WEEK $
				HOURS/ WEEK	COST $/ WEEK		HRS/ WEEK	$	DAYS TOTAL	COST	DAYS TOTAL	COST		
A	39	4	4	23.92	291	3.5					10	23		314
B	10	3	3	21.63	263	4.0								263
C	66	1	3	14.82	189	4.0								189
D	43	2	3	15.88	189	4.75	1.5	18						207
E	54	3	4	14.02	153	7.0								153
F	39	5	3	13.43	160	6.5			14	12			21	193
G	17	3	4	19.11	252	7.5					56	172		424
H	33	4	3	19.91	224	4.5	2	24			45	130		378
I	52	3	3	22	229	9								229
J	32	5	3	14	143	6.5							21	164
K	30	4	3	16	163	8.0			21	16				179
L	21	6	4	21	193	2.5					14	31		224
M	32	2	4	19.5	194	5.5					24	74	21	289
N	39	4	3	21	219	2.8	3.5	42						219
O	32	2	3	14	136	5.5								136
Q	30	2	2	23	238	13.0			30	25			21	284
R	37	2	1	21	290	4.75					3	7	21	318
S	60	2	3	16.5	183	8.5								183
T	32	3	3	27	254	5.5								254
U	27	4	4	25	316	6.0							21	337
V	50	3	3	28	279	3.0					7	27		306
W	49	2	2	28	283		3	36	*					319
X	23	2	3	42	375	10.0	5	60	10	8			21	464
MEAN				21	227	5.75								262

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SOURCES FOR TABLE 7.15

Column

(1) Code letters used to indicate individuals in the pilot study of attendant care allowance and service models.

(2) Barthel Score of dependency in activities of daily living used elsewhere in this Report. (Table 4.9, final reassessment.)

(3) Number in household as described elsewhere give an impression of the size of the domiciliary unit and the actual or potential caring resources available.

(4) The number of bedrooms is used here to give an impression. Accommodation occupied is the number of bedrooms in the house or home unit or apartment from the best available estimates by field workers.

(5) Attendant care used is taken from Table 7.10 (Service model, actual hours used; Allowance model, hours allowance received for).

(6) These costs were obtained from the summary tables given earlier in this Report - Tables 7.5 and 7.8.

(7) Source: Table 7.10.

(8) Source: Table 7.11 and the cost estimated was provided by Home Care Service of NSW and is quoted in the text.

(9) Use of nursing home for short stays/respite care as indicated in Table 7.13. Weekly cost is a pro rata allocation (expressed on a weekly basis throughout the period of pilot participation which varied from person to person) of the total cost for the stays, as indicated.

(10) Table 7.12 and the data prepared by AHRC (1982) as updated in current dollars, expressed on a weekly basis throughout period of participation in pilot (Appendix F). Both capital and operating costs are included.

(11) Domiciliary Nursing Care Benefit. It should be noted that all participants are eligible for this benefit to be paid to a carer but few have in fact applied. If an Attendant Care Scheme is introduced it is unlikely that any person would receive both DNCB and Attendant care benefits.

7.6.1 Average Cost Comparison

We have noted previously that the Commonwealth Government's share of the cost of nursing home care under existing financing arrangements, on a bed day basis, does not relate very closely to either the care required or care actually received by patients.

Using the current total subsidy per bed per week is therefore a reasonable approximation to the cost to government of such care. The following table presents the comparisons between the cost and the average cost of attendant care. It can be seen that on this basis the cost of the average attendant care service package for the sample under study is consistently less than the average cost of the nursing homes compared, $227 per week compared with $351 per week. When the costs of institutional care used on a short term basis by some attendant care clients for respite or acute episodes of hospitalization are included, the average costs of attendant care rises by $35 per week. When individual cases are examined for which data in Table 7.15 are presented it will be seen that a small number of them (3) out of 23 in the pilot study have total package costs which exceed the average cost of nursing home care.

Table 7.16: **Average Cost Comparisons**

	Average Cost of Attendant Care Service	Average Cost of Packages in Table 7.15	Average Cost of Two Nursing Homes
All participants	227	262	351
Service Model	215	265	
Allowance 1	182	206	
Allowance 2	277	308	

7.6.2 Changes in Care Mode

Perhaps a more meaningful comparison is to compare the effects on costs to government of the recipients of attendant care being moved into nursing homes if the scheme were not to be continued. This "place taking test" will of course only be strictly meaningful if there is a significant change in the way nursing homes are financed towards a more patient-specific system. This comparison is presented in Table 7.17 .

Table 7.17: Comparison of Costs of Attendant Care Clients if moved to Nursing Homes

Hours of Care	Total hours per week	Estimated cost of these hours if in Nursing Home	
		1	2
Service Model Clients:			
Average 17.84 hours paid care plus 5.7 voluntary hours	23.54	249	301
Allowance Model 1:			
Average 18 hours allocated plus 5.7 voluntary hours	23.2	246	297
Average 16.5 hours used plus 5.7 voluntary hours	22.2	235	284
Allowance Model 2:			
Average 26.37 hours allocated plus 6.3 voluntary hours	32.7	346	418
Average 24.3 hours used plus 6.3 voluntary hours	30.6	324	391
Average for all	26.7	276	331

It can be seen in this table that the cost to government of servicing the same needs for these clients, using the direct care hours received in the pilot attendant care scheme as the basis, would be very similar to the estimated current average costs per bed per week under the existing funding arrangements. Any cost saving of the attendant care scheme in this calculation would be largely attributable to the unpaid care time provided by relatives.

The reverse comparison which is also of interest is to consider what would differ to government cost if the nursing home residents were moved out into the community and received levels of attendant care equivalent to the pilot scheme participants.

We do not have detailed data about the Barthel Scores or dependency of the nursing home residents but the data (Table 7.17) presented above give an impression of the average amounts of care time required. The care requirements of the nursing home patients are very similar to those in the attendant care scheme and suggest that the costs would change very little if at all.

One other major source of variation in the costs would appear to lie in the cost differences attributable to the type of ownership and organisation of nursing homes. Particularly where some of the state owned nursing homes are involved, the average bed day costs appear to be rather higher than in the deficit funded nursing homes we have used as examples. The overall share of government in the cost is much the same allowing for similar levels of patient contributions and so on. Under the existing subsidy arrangements variations in costs do not change the amount of subsidy per bed day and hence cost of the programme.

7.7 Summary and Conclusions

Costs have been considered for the specified group of the pilot study which was severely physically disabled adults, who were capable of and willing to obtain their own personal care. This target population had a severe personal care handicap such that at least two hours assistance per day was required for personal care. Persons within this category who do not have the intellectual capacity for managing their own affairs, although not excluded were not represented in the applications and were therefore not represented in the sample.

In the absence of paid or voluntary personal care in the community this group would be eligible to enter a nursing home which would attract government subsidy. Nine of the attendant care pilot participants had previously resided in deficit or state funded nursing homes for periods ranging from 2 to 7 years.

The pilot project has shown that a scheme sensitive to individual needs need not prove as expensive in terms of unit costs as institutional services currently subsidised by government. At the same time, however, it is recognised, that cost to government for this group of people, would be greater if an attendant scheme were introduced, because the majority do not occupy nursing homes places.

The pilot project enabled participants to buy the hours (level of service) they determined met their needs. These needs were seen to be influenced by a combination of factors including family/household arrangements and level of disability.

The literature expands on the debate that cash costs are not necessarily co-incident with resource costs and that cost should not be the only factor which determines the pattern of care. None of the participants in this study can survive without personal care assistance, it is a question of who should provide this care and whom the government should pay to provide it and how much.

An examination was made of cost to government had the participants been prepared to remain or live within institutions to which government had funding obligations. If these funding arrangements were reassessed to provide paid assistance for Attendant Care in the community ,the pilot project indicated that in the majority of cases care of the type provided by the attendant care pilot scheme is a less costly alternative to government than subsidy for that person in a nursing home. The services provided are governed by different structural constraints.

The numbers in the study were small and as such while indicating a range of needs, may limit the extent they may be taken as representative of the disabled population as a whole, in terms of physical dependence, family structure or socio-economic status. As in other studies we found that the pattern of household composition influenced the demand for paid services. Changes in the patterns of this composition and location may reduce the level of support available or desired. The pattern of Attendant Care Services available needed to be flexible and responsive to individual needs. The cost to government is diminished by the presence of unpaid assistance which substitutes for formal support services.

The cost to government could be higher if caring for the majority of study group members in institutions than if they were retained in the community receiving the support that would make this possible.

8

EXISTING SOURCES OF PERSONAL CARE IN NSW

Disabled people, largely dependent on voluntary personal care from family and friends, have been able to supplement this to a certain extent with care provided by government subsidised agencies (the Home Care Service of NSW and domiciliary nursing services) or with care paid for privately (private nursing agencies or individual employees). Care has also been available in institutions.

The advantages, disadvantages and costs involved in each of these sources of care are examined in this section.

8.1 The Home Care Service of NSW - A Survey of Severely Disabled Clients

8.1.1 Historical Perspectives

The Home Care Service of N.S.W. a semi-government body incorporated under the Community Welfare Act, 1984, is governed by a Board of Directors, directly responsible to the N.S.W. Minister for Youth and Community Services. It is similar in some respects to the more familiar home help services operating in other Australian states.

The present management structure comprises a paid Head Office Staff responsible for financial management, policy development in all areas and implementation of new policy, a small paid regional structure with an advisory and educational role and voluntary locally elected branch committees with the responsibility for management at the local level.

Its origins can be traced to the Housekeepers Emergency Service, established in 1943 to assist wartime housewives with husbands away at war and no other help in times of pregnancy or illness. This initial emphasis on child care and family life was combined with a concern for the aged when the Home Aide Service was introduced in 1954. There has been a continuing shift in emphasis from full time housekeepers for families to part time household assistance for elderly persons, with the relatively recent addition of personal care services for persons of any age.

The Home Care Service of N.S.W. began providing a personal care service for disabled persons in 1979, as a natural extension of the existing services carried out by non-medically qualified home aides.

Initially the service was of a pilot nature offered through two branches only, Willoughby and Bathurst, funded by a special grant from the N.S.W. Department of Youth and Community Services.

By 1981, the International Year of Disabled Persons, the Home Care Service (still known at that time as the Home Help Service of N.S.W.) was actively implementing services in all branches to provide "positive support to disabled persons and families with disabled members". The service at that time included preparation and serving of meals, assistance with eating, assistance with dressing, mobilisation and personal grooming but specifically excluded full bathing or showering "as full bathing or showering requires a trained nurse", (Guidelines for the Provision of Home Help Assistance to Disabled Persons/Families with Disabled Members, 1981). Availability of additional funding through the Wage Pause Programme during 1982/83, a time when the level of HCS funding (state grants matched by Federal grants under the States Grants (Home Care) Act, 1969), was hopelessly inadequate to meet the increasing demand for all types of services, enabled a rapid expansion of the service to disabled people between 1982 and 1984. Education Officers were employed to work with groups of branches for six months at a time to facilitate the introduction of services for disabled people by actively seeking out clients in need of such services, training Home Aides for this type of work and generally increasing awareness at the Branch level of HCS policies with respect to services for disabled people. The services actually offered underwent an evolutionary process of change over this period, resulting in the present comprehensive service which includes all assistance "which a family member could reasonably and confidently be expected to give without endangering the well being of the client "(Home Care Service of N.S.W., Policy Manual, 1984). Personal care for people with a physical disability now includes assistance with showering/bathing, toileting, hair, fingernail care, skin care, shaving, urinary and bowel care.

A doubling of the HCS budget for 1983/1984 meant that services previously provided with wage pause program funds could be continued as part of the ongoing service and new clients could readily be provided with service. The less than maintenance budget allocated for 1984/1985 does not auger well for the continued growth of services for disabled people.

Expansion of the services for disabled people has been rapid and at times uneven across branches and subject to the vagaries of funding from one year to the next. It is therefore crucial that the reader of any written description or analysis of the service be aware of the historical context in which it was written. The data presented in this chapter is based on information provided by HCS Branch Co-ordinators in mid 1984 i.e., at a time when each branch had had an Education Officer for six months at some time during the preceding two years and at a time when funding was adequate to meet all assessed needs and on information provided by clients interviewed in March/April 1985 by which time the effects of funding constraints were starting to appear.

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8.1.2 Rationale for Survey

By mid 1984 HCS personal care assistance had been available in Sydney for little or no cost (under a "pay according to means" policy), for at least twelve months and for considerably longer in some areas. Not only had it been available, it had also been actively "marketed" by the education officers employed for this purpose. Priority to disabled clients needing a large number of hours of assistance per week, is HCS policy. It therefore seemed reasonable to assume that the number of people who had seen fit to use the service on a regular basis, would give an approximate indication of the number of people likely to apply for any new service of a similar nature such as an attendant care service or allowance.

Disaggregation of client numbers into categories defined in terms of Attendant Care Pilot Study criteria was not possible from HCS Head Office records. It was therefore necessary to analyse branch records directly.

8.1.3 Method

The target clients for inclusion in this survey were those clients aged between 16 and 65 who require daily assistance from someone in order to be able to perform key personal care tasks such as bathing, dressing, grooming, toiletting, transferring and feeding. Clients needing such assistance for a temporary period only (e.g. as a consequence of episodic illness) were not included. All clients included in the survey could thus be described as permanently, severely disabled and having a personal care handicap. Clients meeting these criteria were included, whether or not they were receiving personal care services from HCS (some were receiving housework assistance only).

A researcher visited the 39 HCS branches in the Sydney metropolitan area (including Camden/Campbelltown and Blue Mountains between May and August 1984. The co-ordinators answered questions about all aspects of personal care service for disabled clients and provided access to individual client records. Forms used for recording information are included in Appendix B. A summary of the co-ordinator's responses to each question are included in Appendix G.

Each co-ordinator was asked to identify the clients who they felt met the requirements for inclusion as described by the interviewer. In many instances client records were incomplete or contained insufficient detail to enable the interviewer to include or exclude with certainty and to complete data sheets. The co-ordinator was asked for additional information about all doubtful clients. The co-ordinator's personal knowledge of her clients was in most cases sufficient to supply the missing information, any remaining doubts being clarified by a phone call by the coordinator to an aide who regularly works with the client in question.

8.1.4 Survey Data

A total of 435 clients were identified as meeting the criteria for inclusion. Of these, 236 were receiving personal care services, and 199 were receiving housework services only. Information is reported separately for these two groups of clients. The personal care service users may or may not have been receiving housework services as well.

8.1.4.1 Personal Care Service Users

The data in this section relates only to the target population of clients defined in section 8.1.3

Distribution Across Branches
Although thirty five of the 39 branches surveyed had at least one client in this category, seven branches between them account for 107 of the 236 users (45%). This is partly, but by no means entirely, due to variation in branch size. Equal numbers of male and female clients were found overall, but more than twice as many males were using 14 hours or more per week while twice as many females were using 5 hours or less per week.

Living Situation
The majority live with at least one able-bodied person (77%) while 12% live alone and 11% live with a person(s) who is also disabled. The availability of personal care service has in fact made it possible for disabled people to live alone or with other disabled people only, in non-institutional accommodation, an option previously just not possible. The Australian Quadriplegic Association, the Crippled Children's Society of N.S.W. and the Spastic Centre of N.S.W. have all been able to assist members find independent accommodation on the basis that personal care services would be available through the HCS of N.S.W. The majority are not employed (71%) with those who are, working full time (16%) or part-time (6%).

Other Personal Care Assistance
Information was sought regarding the provision of personal care assistance by persons other than HCS aides. It was not always known whether nurses (district/community/private) were visiting a client regularly and whether personal care tasks were being performed during such visits.

There would appear to be differences between the branches in terms of the percentage of personal care clients who receive assistance from a nursing organisation in addition to that provided by the HCS, possibly reflecting different interpretations at the local level of the role of medical supervision of personal care work. The nature of the working relationships between the HCS and nursing organisations varies across regions within the Sydney metropolitan area.

Information was also sought about the provision of assistance by household members or other relatives. Due to some uncertainities in responses the information in Table 8.1 should be regarded as an approximate indication only.

Table 8.1: Sources of Personal Care Assistance - Personal Care Users

Source of Personal Care Assistance	% of Personal Care Users
HCS only	15.7
HCS + household member	43.8
HCS + visiting nurse	9.4
HCS + visiting nurse + household member	27.3
HCS + non-resident relative	1.4
HCS + visiting nurse + non-resident relative	2.2

Overall 39% HCS personal care service users were also receiving domiciliary nursing services.

Hours of Personal Care

Five hours/week or less of HCS personal care assistance was being used by 45% of clients surveyed.

The co-ordinators reported that none of these clients had been allocated fewer hours than requested. Clearly this level of assistance must fall into the category of 'respite' care to assist a household member who is providing most of the care required.

Table 8.2: Hours of Personal Care per Week

Personal Care Hours/Week	% of Personal Care Users
Less than 5 hours	44.9
10 < 5	26.3
15 < 10	17.4
20 < 15	3.3
25 < 20	4.7
< 25	3.4

Thus 40 persons in the Sydney metropolitan area are receiving 14 or more hours per week of personal care assistance from HCS and 19 of them receive 20 or more hours.

Personal Care Tasks Performed
Table 8.3 shows the proportion of target clients receiving each category of assistance rather than number of hours allocated for various types of services.

Table 8.3: Tasks Performed for Clients

Tasks Performed	% of Personal Care Users
1. Minding/supervising*	16.3
2. Bathing and dressing	22.8
3. Bathing/dressing/toileting	31.9
4. Bathing/dressing/special toileting**	17.2
5. Grooming only	5.6
6. Therapy Exercises only	5.6

* may include the preparation of a meal, feeding, toileting during the period of "minding".

** 'Special toileting' refers to the presence of catheters, uredomes etc. and/or the need to use enemas.

NOTE: Clients counted in categories 2, 3 and 4 may also receive assistance of the other types but have not been counted twice.

Hours of Housework Assistance
Some personal care users also receive assistance with housework

Table 8.4: Hours of Housework Assistance - Personal Care Users

Housework Hours/Week	% of Personal Care Users
0	44.1
1 to 5	41.9
6 to 10	11.5
< 10	2.5

Clients receiving a large number of housework hours fall into two categories:-

i) disabled clients living alone or with other disabled people only

ii) disabled women responsible for households which include children

Thus some of the "housework" hours are in fact "personal care" of young children.

Length of Service
The "newness" of the service is highlighted by the fact that 50% of present clients have been using the service for eight months or less. In fact 82% of the present clients have been using the service for two years or less. The few clients of long standing are those who had been receiving housework assistance prior to the availability of personal care services.

Table 8.5 Disabling Conditions - Personal Care Users

Disabling Condition	
Spinal Injury	27.2
CNS Diseases	19.2
Circulatory Diseases	7.4
Childhood Diseases	5.1
Congenital Conditions	22.1
Arthritis	4.7
Intellectually Disabled	5.1
Psychiatrically Disabled	3.9
Brain Injury	2.6
Cancer	1.3

8.1.4.2 Non-Personal Care Users

Once again a small number of branches (6) account for 90 of the 199 non-users (45%). Only two of these six branches, however were also in the set which accounted for 45% of the users.

Only 36.5% of this group are males. The majority (72.7%) live with at least one able-bodied person and 86.7% do not work.

Table 8.6: Source of Personal Care Assistance - non users of HCS Personal Care

Source	% of Non-users
Domiciliary nursing + household member	40.8
Institution part-time	1.1
Attendant care pilot	1.6
Household member only	56.5

Hours/week of Housework Assistance

The distribution of hours is very similar to that reported for the personal care user group.

Table 8.7: Hours of Housework Assistance - non users of HCS Personal Care

Housework hrs/wk	% of Non PC Users
1 to 5	88.4
6 to 10	10.1
> 10	1.5

Compared with the personal care user group, the non-user group has a much higher proportion of people with MS, stroke, brain injury and intellectual disability and a much smaller proportion of those with spinal injuries, suggesting that the non-user group may on average be less severely disabled and thus not in need of as much personal care assistance.

8.1.5 Characteristics of the Personal Care Service

The most striking feature of this service is the variability between branches with respect to assessment procedures, selection of aides, training of aides, cost of service to the client, tasks performed, advertising of availability of service and average hours per week allocated per client. Several factors give rise to this variability:-

- relative independence of branches (gradually being reduced) each with its own management committee
- demographic differences between areas in numbers of disabled people and availability of aides
- the time of appointment of education officers specifically employed for the disabled program
- the length of time co-ordinators have been with the service

Advertising Availability of Service
Given the uncertainities surrounding adequacy of funding, it is not surprising to find that most co-ordinators do not actively advertise the service beyond ensuring that all other relevant agencies (general practitioners, hospitals, community nurses, special schools) have up to date information.

A doctor's certificate is not required to receive service but a significant number of referrals come from this source. Eight co-ordinators specifically mentioned giving talks to local group meetings and on local radio, three had contacted every doctor in their area, six had already (or would in the near future) have articles published in a local newspaper and twelve had contacted disabled organisations or services.

Selection of Aides
HCS operates a Service based rather than a client based model i.e. a pool of aides is employed and these are then allocated to clients requiring service. Although only one co-ordinator said she definitely would not employ aides suggested by clients and only a few were hesitant fearing that "it may lead to problems", only five had actually done so. Each aide typically works for several clients such that the desired number of hours per week is worked.

The first source of aides for a new client, therefore, is the existing set of aides working for the branch. When HCS began offering personal care service not all of the existing aides were willing and/or able to undertake this type of work. Most had been accustomed to working only during normal business hours (or school hours for some) and did not work diring school holidays. Personal care work is

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often "out of hours" and required every day of the year. Branches are gradually phasing out their staffing problems by giving preference, when selecting new aides, to those who are flexible enough to work at the times required.

Many trained nurses or nurses aides apply to work as aides. A third of the co-ordinators specifically give preference to nurses when selecting personal care aides while one discriminates against nurses.

Seven co-ordinators mentioned that they had experienced difficulty in recruiting sufficient numbers of "good" aides capable of doing personal care work and willing to work the early/late/weekend hours required.

Training Aides
There is a heavy dependence at this stage on trained nurses, directly or indirectly, to assist in the training of aides, albeit at a minimum level. This dependence arises in four main ways:-

a) training is unnecessary because the aide is a trained nurse (specifically mentioned by 9 branches)

b) community/district nurses provide on the job training for new aides (specifically mentioned by 7 branches)

c) training provided by staff at a local hospital, nursing home or rehabilitation facility (specifically mentioned by 13 branches)

d) office staff or committee members of the branch are trained nurses and assist in training aides (specifically mentioned by 6 branches)

Community/district nurses in some areas have refused to be involved in the training of aides. Fourteen branches placed a heavy emphasis on the clients' responsibility to provide whatever training is required, while only two branches would not allow aides to commence work until they had received 'proper' training. Four branches specifically mentioned training for a new aide being provided by an aide who had already worked for the client concerned.

Underlying concern was expressed by many co-ordinators that aides were being put into situations which are potentially dangerous to themselves or their clients.

Of the nine co-ordinators who felt that clients could provide all the training that is required, eight had seven or fewer clients in the severely physically disabled category.

Cost of Service to the Client

Some branches have adopted a policy of making no charge to disabled clients for personal care services on the grounds that "domiciliary nursing services are often free." Other branches still charge "according to means to pay". Clients receiving a large number of hours/week typically pay less per hour than those using few hours. In most cases cost would not be seen as a deterrent to using the hours required. The maximum of $9.50/hour(mid 1984) is charged when an insurance company is responsible for payment.

Approximately one third of the personal care user group make no payment for the service.

Tasks Performed

The range of tasks performed by Home Aides depends on the client's individual needs, the client's and/or co-ordinators' views as to whether some tasks require a medically qualified person for their execution or not and the total number of hours that can be allocated to each client.

At one end of the spectrum unqualified aides are capably assisting with whatever is required (including catheter care, leg bags, uredomes, enemas, lifting, showering, dressing, feeding) under the direction of the client and/or his family. At the other extreme assistance is provided with therapy exercises only.

Advertising Personal Care Service

The majority of co-ordinators find that they are using up all the hours available just responding to referrals (without advertising) and would be afraid to raise people's hopes by advertising for fear of not having sufficient hours to meet the increased demand.

Six co-ordinators give talks to local groups when requested, ten actively seek to make contact with local doctors, hospitals and organisations, six place advertisements in local newspapers and two seek out disabled people who may be able to use the service. Many mentioned that an Education Officer, attached to the branch temporarily, had actively sought out disabled people in the area and that these are the people who are now using the Service. Co-ordinators, for the reasons cited previously, have not continued this process.

Additional Services Needed by Disabled People

Co-ordinators were asked to nominate what additional help would be required by disabled people using HCS personal care service. Branches fall into two main groups on this issue:-

(a) twelve co-ordinators work on the principle that HCS aides can do whatever is required and therefore clients would not need assistance from any other agency.

(b) eight co-ordinators work on the principle that services should not be duplicated and would therefore only have aides cooking meals,providing transport etc. if such services could not be obtained through other local agencies such as Meals on Wheels, volunteer transport etc.

Five co-ordinators would arrange district or community nurses for clients needing special toiletting assistance i.e. catheters and enemas. Another two have arranged for district or community nurses to "keep an eye on things" when they have aides doing this type of work.

The Problems Associated with Personal Care Service

The most frequently mentioned problem was difficulty in finding and retaining "suitable" staff willing to work "out of hours".Suitability criteria usually include nursing training or at least some previous experience with relatives or in a nursing home, appropriate standards of personal hygiene and reliability.

A corollary of the first problem is the relatively greater use of co-ordinators' time per client if personal care is required. There was a general feeling that staffing formulas should allow for the extra time involved.

The responsibility of having clients totally dependent on HCS aides for survival creates anxiety as does the client who makes unreasonable demands of aides. These problems were, however, mentioned infrequently. Five co-ordinators, four of whom had more than ten clients in this survey, felt that arranging personal care service presented no greater number of problems than did arranging any other type of service.

8.1.6 Selection of Sample for Personal Interview

A sample of thirty personal care users was selected for individual interview.
The interview sample included:

i) people using 5 hours or less, and

ii) people using 14 hours or more with representation in each group of a variety of disabling conditions. The disproportionate representation of men and women in each of the above groups (due mainly to the larger proportion of spinal injuries in the '14 hours or more' group) was reflected in the interview sample.

Eight of thirty selected were not available for interview (two branches did not want their clients to be interviewed (4 people), three were currently having serious health problems and one could not be contacted). Each of the remaining twenty two people were interviewed in their own home. Two were not in fact receiving any personal care assistance from HCS (this being provided by a relative) but were receiving housework assistance only. The final interview sample thus comprised twenty people.

8.1.6.1 Characteristics of Sample

As intended, this sample was very similar to the pilot sample. Two individuals however only needed personal care assistance when suffering from skin problems (a paraplegic and a hemiplegic). At other times housework assistance only was required. Table 7.8 shows the causes of disability represented.

Table 8.8: Cause of disability - personal interview sample

Cause of disability	Number in Sample
Spinal cord injury - road accident	3
- sporting	4
- work	1
- other	1
Polio	2
Multiple sclerosis	1
Transverse myelitis	1
Spinal growths	1
Arthritis	1
Arthrogryphosis	1
Cerebral palsy	1
Muscular Dystrophy	1
Muscular Atrophy	1
Stroke	1
TOTAL	20

The person with post stroke hemiplegia was deleted from further consideration as she did not meet the eligibility criterion of severity.

Eighteen were functionally quadriplegic, one paraplegic but with constant skin problems, all confined to wheelchairs for mobility (7 electric, 12 manual), 74% expected the extent of their disability would remain the same (26% expected to deteriorate), six reported additional health problems (urinary tract infection, kidney, heart, blood pressure, skin, psychiatric) and nine had lived in an institution for an extended period at some time in their life. Two others had spent short periods of time in an institution for respite care.

8.1.6.2 Sources of personal care assistance

The amount of assistance provided by HCS ranged from 3 hours to 35 hours per week.

Four people (receiving 20, 21, 17 and 35 hours/week from HCS) received no additional personal care from other sources. Domiciliary nursing services (one private, four government subsidised) were providing some personal care for five people.

In each case except one (where a nurse was required to apply dressings to leg ulcers and for practical reasons, bathed the person as well) the tasks being performed by nurses, were the same tasks being performed for other people by HCS aides. Some are bathed by nurses on "bowel" days only and one person hires a private nurse at weekends as her HCS branch had been unable to provide service at that time.

The amount of assistance being provided by household members varied from half an hour per week to twenty hours per week.

Four people were not receiving as many hours from HCS as they had asked for and another six were not getting as many as they would really like. The reasons for this included shortage of hours or money at the branch, aides not available for the times required (weekends or evenings) or that they simply did not like to ask for more.

8.1.6.3. Assessment

Assessment procedures used to determine hours to be allocated and fees to be charged vary considerably from branch to branch. The cost/hour of service is not reported as it is invariably dependent on the number of hours being used. The amounts paid per week are given in Table 8.9. As discussed previously, some branches have adopted a policy of making no charge for personal care. Two people were not aware of ever having been assessed (just asked for the hours they wanted); the rest had all been assessed at some time in the previous twelve months, either when they first applied for assistance or when they had requested an increase in hours (3).

Table 8.9: Cost/week to HCS clients

$/week	Number in sample
0	6
$5 or less	6
$6 - $7.50	2
$12.25 - $15.00	2
$20.00 - $21.00	2
$28.00	1
TOTAL	19

8.1.6.4 Perceived degree of Control

Selection of Aides

Eight people indicated that they do their own advertising, interviewing and selecting and send the people they select to the branch to be signed up. In effect all the branch does is pay the aides on the basis of timesheets submitted.

Eleven people had aides sent to them by the co-ordinator but five had been advised that they could request a change of aide if ever unhappy with the choice (one person was aware, however, that although he can theoretically request a change, the branch "doesn't like the paperwork this generates").

Training of aides

As far as three clients were aware, almost all of the training had been done by themselves or other family members, although three knew that their aides were trained nurses. Sydney Home Nursing Service had accepted responsibility for training aides for one person and one client felt that his HCS branch was becoming more involved with training quite unnecessarily, encouraging aides to attend by paying them. In his experience "no aides had ever benefitted except financially from any of the training programs run by the branch".

When aides come

The individual aides, rather than the branch, may impose restrictions by being unwilling to work at certain times. Three people had experienced difficulties getting aides to come later in the evening to transfer them to bed and could mean going to bed by 7.30pm if household members are unavailable. The majority indicated that they had satisfactory control over when assistance is provided.

Backup Arrangements
Seven people had no back up arrangements other than household members, seven find that having more than one regular aide means that any absences can always be covered by the other aides and five rely on the co-ordinator to find a temporary fill-in, an arrangement found to be the least satisfactory of the three.

8.1.6.5 Preference for service or allowance

Only four people expressed an absolute preference for an allowance with which to arrange attendant care independently and four "wouldn't mind receiving an allowance" but could foresee potential disadvantages ('could be a hassle', 'might affect tax', 'might be hard to find suitable honest aides'). Twelve people definitely would prefer to continue in a service model ('like them to do the paperwork', 'I know how to get the best out of the HCS system', 'wouldn't be able to afford to advertise myself', 'prefer HCS to sort out suitable honest aides to employ').

Despite the resounding vote of confidence for the HCS several suggestions for improvements were offered, principally

- portability of hours between branches
- accumulation of unused hours from week to week
- wider selection of aides to allow splitting of allocated hours across more aides to facilitate backup
- greater availability of service at weekends and on public holidays
- a more flexible service with respect to training so that it is not assumed problems experienced by a few individuals are likely to be encountered by all.

8.1.6.5 Improvements in quality of life

The most frequently mentioned improvement was increased independence for self and/or family. The number in brackets indicates the number of people giving each of the following responses to the question.

"What improvements in your life do you feel are due to your getting personal care assistance from HCS?"

- allowed me to leave the nursing home (4)
- kept me out of a nursing home (3)

- relieves family (4)
- has increased the choice of living arrangements (1)
- important for relationship with wife/husband (3)
- gives freedom from family - will soon move to own place, minimise feelings of dependency (2)
- replaced parents who were no longer able to lift (1)
- independence (9)

8.1.7 Summary and implications

1. Approximately 200* people aged between 16 and 65 years with a severe personal care handicap have been receiving personal care assistance from the Home Care Service of NSW in the Sydney Metropolitan area. Forty of them receive as many hours as the participants in the pilot study.

2. The service has been directly responsible for enabling people to leave institutions and has prevented the involuntary admission of others.

3. The service characteristics with respect to availability, coverage and client independence in aide management vary from branch to branch and will continue to do so despite management policies, until a complete regional management structure is established.

4. Hours of service may be limited to any one individual depending on competing needs.

5. Hours of service may be decreased due to increasing competing needs or reduction in budget allocation at state level.

6. Hours are not automatically transferred with a client who moves from one area to another.

7. Hours not used in a given week may not be transferred forward for later use.

8. Home Care Service of NSW and domiciliary nursing services are in some cases providing the same service on different days to the one household.

9. A degree of consumer control has been possible at some branches due to the election of clients with disability to the local management committee.

10. The majority of users interviewed were very satisfied with the service they were receiving and would prefer this mode of assistance rather than receiving an allowance. The dissatisfied clients were of the opinion that they did not require the services of an intermediary to arrange their own care but did require financial assistance to do so.

11. Updated information indicates that budget levels as at October

1985 have created waiting lists for service at many branches.

* the original number of 236 has been discounted by the rate indicated in the sample interviewed, to delete those incorrectly included.

8.2 Domiciliary Nursing Services

Home nursing is provided by different organisations in different regions of the Sydney metropolitan area and by more than one organisation in some regions. The Sydney Home Nursing Service, funded as a public hospital, provides service in the older areas of Sydney while the NSW Health Department operates a service through its Community Health Centres in areas not covered by SHNS. In addition local government in some areas provides a separate service.

Payments for visits ranges from nothing to approximately $6 per visit or in some cases clients are advised that donations will be accepted. Some services advise and assist clients to apply for the Domiciliary Nursing Care Benefit to help defray the cost of service for the client.

Disabled people report the following disadvantages for them of using home nursing services for personal care:

. typical staffing patterns do not provide for regular evening or weekend service and do not allow sufficient client control over when service is delivered
. nurses, by virtue of their training, expertise and legal obligations, expect to 'call the tune'
. attendant care tasks do not require nursing skill when the person being cared for is of sound mind
. funding legislation favours the employment (from a state perspective) of trained nurses
. non personal care tasks such as light meal preparation, tidying up etc are not performed by nurses
. present budgets do not permit the allocation of sufficient hours to any one individual or the guarantee of permanence of hours once allocated.

8.3 Privately Financed Non-Institutional Care

Every effort was made to locate people meeting pilot study eligibility criteria who purchase personal care assistance at their own expense.

Services have been purchased

- . in institutions
- . from private agencies
- . from government agencies
- . from individual providers

Examples of the purchase of care through government agencies at subsidised prices (for which there is no strictly imposed means test) have been included in 8.1 and 8.2.

Eight people using one or a combination of the other methods listed, were interviewed in depth concerning the cost of services purchased. The disabling conditions in this group are spinal injury (5), post polio (1), multiple sclerosis (1) and brain stem injury plus leg amputation (1). Three in this group have received Third Party motor vehicle accident settlements, one an accident insurance settlement, one receives regular payments under a workers' compensation claim, one received a lump sum settlement from a government department and one has substantial independent means in addition to services provided by the Department of Veterans' Affairs. The eighth person pays for care from her invalid pension. Varying amounts of voluntary care are used in each case.

8.3.1 Payments made for Personal Care

		Cost/week to individual $
Case 1	Private nurses	90
	Personal assistant cum housekeeper	240
	TOTAL	330
Case 2	Private nurses	120
	Live in housekeeper (free board)	150
	TOTAL	270
Case 3	Private nurses	100
	Live in housekeeper (5 days free board)	100
	TOTAL	200

Case 4	Government subsidised nursing (Monday to Friday)	nil
	Private nurses (Saturday,Sunday)	60
	Daily attendant at work	200
	Overnight attendant (2 to 3 per week)	135
	TOTAL	395
Case 5	Private room in Nursing Home (Monday to Friday)	188
	TOTAL	188
Case 6	Private nurses 8 hours/day (paid for by Dept of Vets. Affairs)	nil
	Private nurses	270
	TOTAL	270
Case 7	Private nurses	189
	TOTAL	189
Case 8	Attendant	15*
	TOTAL	15

* $15 is not an accurate indication of the real cost in this case because this person trades her services as, amongst other things, a babysitter in return for personal care assistance. She lives alone.

8.4 Institutional Care

Patients in private participating nursing homes receive the Commonwealth ordinary or extensive care nursing home benefit. This is paid to the proprietor of the nursing home who offsets it against the charge to the patient. In addition, the patient pays a statutory minimum patient contribution which is 87.5% of the combined single age pension and supplementary assistance.

Church based groups, religious organisations, local government and community organisations may operate charitable and religious deficit financed nursing homes. Nursing homes eligible for deficit financing must lodge an annual budget to which (after examination) advances are subsequently made against an approved budget deficit.

These homes operate under the Nursing Homes Assistance Act 1974. This legislation provides that patients cannot be charged more than the statutory patient contribution. There is in addition, provision that the patient contribution can (subject to departmental approval) be reduced in cases of financial hardship.

The charitable and religious participating nursing homes operate under the National Health Act 1953. Accordingly patients receive the Commonwealth Nursing Home benefit and pay a statutory minimum patient contribution.

Some nursing homes approved under the National Health Act 1953 are operated by or on behalf of State and Territorial governments. While patients in these nursing homes receive the Commonwealth Nursing Home benefits and normally pay a patient contribution equal to the statutory minimum patient contribution, any deficit in the operation of these nursing homes is met by the State Government.

The federal government restricts access to nursing home beds by controlling the number of nursing home beds for which subsidies are payable, ie, an NH5 approval does not guarantee access to a nursing home bed. Access has not been restricted for people with the severity of disability required for participation in this pilot project due to priority of access when Community Care is unavailable (paid or voluntary).

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THE POTENTIAL MARKET FOR ATTENDANT CARE IN AUSTRALIA

9.1 Households and Institutions - Australia

The numbers of people requiring attendant care cannot be projected directly from any existing survey results. Acrod (1984) in addressing this issue concluded that the only recent survey based on a fully representative sample of the Australian population and relating to people with disabilities is the Australian Bureau of Statistics (ABS) 1981 Survey of Handicapped Persons. The use of Acrod's (1984) methodology for extracting the relevant figures from the ABS (1981) Survey of Handicapped Persons and the results thus obtained is acknowledged in toto.

The ABS survey figures for "severe handicap" are probably a gross overestimate because the questions on which the level of severity was based asked whether persons ".... ever need help or supervision to...." rather than asking whether a person always needs such help or supervision i.e. the questions do not distinguish between temporary and chronic handicap.

Other questions included in the ABS (1981) survey related to receiving non-medical assistance from outside the home with washing, dressing or feeding and unmet needs for non-medical assistance at home (for washing, dressing, feeding). The data derived from these questions were used by ACROD (1984) to arrive at the figures given here in Table 9.1. The reader is directed to the ACROD (1984) paper for a detailed account of how the figures were derived. Persons with a "mental disorder" are excluded from this table.

Table 9.1: Numbers in Australian Households and Institutions potentially in need of attendant care (derived by Acrod (1984) from ABS (1981) Survey of Handicapped Persons, excluding those with "mental disorders"

Age (years)	Potential Numbers in need			% of total population 1981
	in households	in institutions	total	
0 - 64	6,200	3,600	9,800	0.067
65+	8,400	7,500	15,900	0.109
TOTAL	14,600	11,200*	25,800*	0.177

* Discrepancy due to rounding

9.2 Institutions - NSW

The NSW Department of Health's Census of Long Stay Institutions, Long Stay patients in Acute Institutions and Mental Health Institutions (Nursing Homes), carried out on 19 September, 1984, provides another source of data from which to project the potential users of attendant care, currently living in institutions. The institution types included in this census are hospices for the dying, public and private nursing homes, public and private acute hospitals and mental health and developmental disability institutions. Hospices, acute hospital patients with an expected length of stay of less than six months and residents in mental health and developmental disability institutions with ICD codes other than Cerebral Palsy, are not included in any of the following tables. It was assumed that persons expecting to stay in acute public or private hospitals for longer than six months were "living" there (as happens for example in country areas without nursing homes).

The census classified each person into one of ten possible diagnostic categories "best accounting for stay", 'arthritic', 'orthopaedic', 'degenerative neurological' and 'other' were considered to be the categories most likely to include persons who are medically stable and with the intellectual capacity to manage their own affairs but the inclusion in 'degenerative neurological' of inappropriate cases is acknowledged. 'Mental disorders', 'chronic obstructive airways disease', 'cerebro-vascular accidents', 'heart/circulatory', 'cancer', 'sensory', and 'unknown' were considered much less likely to include persons meeting this project's criteria and were thus deleted from further consideration.

Table 9.2: NSW Long Stay Institutions - persons aged 16-65 years [NSW Health Department Survey 19.9.84]

Diagnostic Categories	Long stay institutions		
	Private Nursing Homes	Public Nursing Homes	Total
Other	199	126	325
Arthritic	46	7	53
Orthopaedic	59	27	86
Degen. neuro	383	149	532
SUB TOTAL	687	309	996
Mental Disorders	694	93	787
COAD	20	6	26
CVA	335	68	403
Heart/circ	43	10	53
Cancer	24	5	29
Sensory	12	10	22
Unknown	6	8	14
SUB-TOTAL	1,134	200	1,334
TOTAL	1,821	509	2,330

The proportion of cases inlcuded for further consideration is indicated in Table 9.2.

Table 9.3: Numbers in NSW Public and Private Nursing Homes, acute public and private hospitals (expected LOS > 6 months) for the categories other, arthritic, orthopaedic and dengenerative neurological

Age (years)	Nursing Homes	Acute Hospitals expected LOS > 6 months	Total
< 16	103	22	125
16-64	996	95	1,091
65+	8,533	464	8,997
TOTAL	9,632	581	10,213

The 996 aged between 16 and 64, in nursing homes, are classified by age and diagnostic category in Table 9.4.

Table 9.4: NSW Long Stay Institutions: Selected diagnostic categories by age and diagnosis

Age	Diagnostic category				Total	
	other	arthritic	orthopaedic	Degen. Neuro	N	%
16-25	22	1	10	12	45	4.5
26-35	44	2	7	20	73	7.3
36-45	55	1	12	53	121	12.2
46-55	68	6	14	110	198	20.0
56-64	136	43	43	337	559	56.0
Total	325	53	86	532	996	100.0

The fact that one third of the group are classified 'degenerative neurological' and aged between 56 and 64 strengthens the suspicion that inappropriate persons are still included.

Further refinement is possible by examining reasons for admission and dependence ratings for walking, dressing and feeding.

Of the 996 aged 16 to 64 in nursing homes with diagnostic categories other, arthritic, orthopaedic and degenerative neurological, 582 were described as having been admitted because of physical dependence (rather than for medical or social reasons) and 516 were rated as incapable of walking.

Table 9.5: Ratings of physical dependence: NSW Long Stay Institutions: persons aged 16-64: other/arth/orth/ degen. neuro.

Activity	Dependence (N=996)			
	independent	aids only	staff required	incapable
Walk	253	114	112	516
Dress	220	26	367	382
Feed	504	103	190	196

The census of Mental Health Institutions (Nursing Homes) reports 158 individuals aged between 16 and 65 (125 of whom live in the Spastic Centre of NSW's nursing homes) for the diagnostic category of cerebral palsy. Some, at least, of these people would need to be included in the potential attendant care population.

It would thus appear that 600 would not be an underestimate of the currently, institutionalised population in NSW who, by this pilot's criteria would be eligible for attendant care, and may well be an overestimate.

On this basis there would be 1800 such persons in Australia. This takes no account of whether these people would want to leave an institution.

9.3 Households - NSW

Organisations including in their membership or providing services for adults with severe physical disabilities were contacted to obtain estimates of the numbers of people meeting the pilot study criteria.

1) The Paraplegic and Quadriplegic Association of NSW.
A survey of a representative sample of this association's membership, undertaken in 1983/84, indicated that 88% of disabled members use wheelchairs, 58% are their own major care provider, 56% of those living in the community said attendant care would prevent them moving into an institution if their current situation changes (e.g. death of a parent, marriage breakdown) and 9.6% live in a nursing home, hostel or hospital.

Translating this into numbers of persons belonging to the association:-

Someone other than self is major care provider		
	- in institutions	144
	- in community	486
Attendant Care would prevent institutionalisation if current situation changed		759

If the above figures are discounted by 11.5% to include only members 60 years of age or younger this association has between 428 and 672 members apparently meeting pilot study criteria.

ii) NSW Society for Crippled Children

Information was obtained in an interview with a spokesperson for the society, the characteristics of the target group being carefully outlined.

The society counts among its members over the age of seventeen years 304 people who need personal care asistance on a daily basis. This number includes 45 people in institutions and 259 in the community.

iii) The Spastic Centre of NSW

Information was obtained in an interview with a spokesperson for the centre, the characteristics of the target group being carefully outlined.

There are 280 people with cerebral palsy working at the centre, 141 living in institutions and 139 living in the community. Insufficient information was available to determine the proportion of these people needing daily personal care assistance and capable of managing their own affairs. For the purpose of this exercise therefore, all will be included as potential users of attendant care.

iv) The Multiple Sclerosis Society of NSW

Field workers for this society were asked to indicate the number of clients seen by them who would be disabled to the extent that they need personal care assistance on a daily basis. The total for the Sydney metropolitan area nominated by workers was 196.

The membership lists of the listed organisations are not mutually exclusive and information regarding the 'coverage' rates is in general not available. Information obtained from the two spinal injuries units in NSW would indicate a very good inclusion rate of persons with

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spinal injuries in the Paraplegic and Quadriplegic Association's membership.

In summary information supplied by organisations point to a minimum of 1,022 persons living in the community, who by this study's criteria, would be eligible for attendant care. On this basis there would be a minimum of 3066 such persons in Australia.

9.4 Estimates Based on Usage rates in California, USA

Details of the IHSS are presented in Section 1 of this report. California's IHSS had been providing attendant care services for twenty four years at the time of the most recent survey of the characteristics of users in 1983. Over that period of time very few Amercian states offered a comparable service so it is reasonable to assume the IHSS had acted as a magnet, increasing the proportion of disabled people in California's population. Estimates of potential attendant care users in Australia, based on the Californian figures would therefore tend to over rather than under-estimate the true figures. Eligibility criteria for IHSS included a means and assets test.

Assuming a population of 25 million in California and 15 million in Australia:-

	IHSS California	Australia (estimates)
Total Recipients	96,850	58,110
Severely impaired	10,500	6,300
Non-severely impaired	86,350	51,810
Severely impaired - Age		
21 years and under	403	242
22-44 years	2,715	1,629
45-64 years	1,697	1,018
65 and older	5,685	3,411
Total	10,500	6,300
Severely impaired - Category		
Blind	191	115
Disabled	5,006	3,004
Aged	5,303	3,182

	IHSS California	Australia (estimates)
Severely impaired - Service Method		
Individual Provider mode		
Payroll Advance*	2,185	1,311
Payroll Arrears	7,700	4,620
Total IP	9,885	5,931
Country Welfare Department	233	140
Contract Agency	361	217
Severely impaired - Memory		
No problem	4,900	2,940
Problems	5,600	3,360
Severely impaired - Orientation		
No problem	5,833	3,500
Problems	4,667	2,800
Severely impaired - Decision making		
No problem	4,773	2,864
Problems	5,727	3,436
Severely impaired - Wheelchair use		
Uses a wheelchair	6,198	3,719
Does not use a wheelchair	4,302	2,581

*Payroll advance is equivalent to "allowance" in the Australian Pilot Project.

Therefore, the severely impaired non-institutional disabled (rather than aged) population, capable of managing their own affairs, would be estimated to be between 3,000 and 4,000 in Australia.

7.5 Conclusion

Estimates based on a number of different approaches would suggest that between 4,000 and 9,800 Australians would be eligible, in terms of this pilot project's eligibility criteria, for an attendant care scheme.

10

CONCLUSIONS AND PARTICIPANTS' RECOMMENDATIONS

This section contains the conclusions drawn from each section and the recommendations made by the participants themselves. A summary of conclusions and related recommendations begins on page viii at the beginning of this report.

10.1 Conclusions

Section 4 Assessment

Eligibility for an attendant care scheme, if such a scheme is to be targeted to the severely disabled, could be determined by,

- functional status score, for example the Barthel Self Care score derived from the Colville Ability Profile, rated by the individual
- eligibility to occupy a bed attracting Nursing Home subsidy

Each measure would be used to certify eligibility. Ideally, the revisions to the regulations governing nursing homes (types, eligibility, subsidies etc) currently being undertaken, should incorporate assessment procedures specifically for the non-aged severely disabled person such that a common eligibility for either nursing home subsidy or 'attendant care subsidy' could be established.

Attendant Time required is not directly related to functional status but is determined by a complex interaction between functional status, social situation and lifestyle.
The amount of attendant time required may be assessed most simply by itemising the tasks with which assistance is required, dividing such tasks into those to be done by a household member (to the mutual satisfaction of the disabled person and the household members involved) and those to be done by a paid attendant.

If attendant assistance is required with household chores as well as for personal care, it is desirable that they be included in the assessment of attendant time, rather than requiring the person to seek this type of assistance from another agency.

An integration of household chores with personal care, particularly in the many cases where "waiting time" during a bowel routine is involved, makes for a very economical use of paid time.

The time required to perform the tasks nominated for attendant care should be determined in consultation with the individual concerned who would describe when and how the tasks are to be done.

The total time required will not necessarily be a simple addition of separate task times but will reflect the individual's routines and priorities.

A procedure for adjustment to allocation of hours is required to respond to changing needs, both on a temporary and permanent basis.

Assessment does not need to be medically oriented but can best be achieved by means of a co-operative exercise involving the assessor and the person being assessed.

Section 5 The Process of Attendant Care

The models, as implemented, differed on some key dimensions and were very similar on others.

i) Selection of attendants

Allowance	by participants, occasional assistance from co-ordinator
Service	some by participants alone, other by participants and co-ordinator together (reflecting a difference between the two co-ordinators).

ii) Payment of attendants

Allowance	by participants; timesheets returned for research purposes only
Service	by co-ordinator according to timesheets submitted

iii) Training Attendants

Allowance	by participants, families, other attendants
Service	by participants, families, other attendants and sometimes by the co-ordinator. Orientation provided by the Co-ordinator.

iv) Workers' Compensation Insurance

Allowance	individual policies, relatively expensive
Service	one policy covered all attendants

v) Travel Reimbursement

Allowance	essentially, paid by participants from 'extra' allowance; less costly per hour of work than the service model; not paid by all participants even when travel was required.
Service	relatively more expensive than allowance model because of distances travelled and the fact that it was always paid.

vi) Length of Shifts worked

Allowance	slightly greater proportion than the service model of shifts less than one hour and three hours or more, reflecting a greater variability in the way in which assessed hours were used.
Service	95% of shifts were 1, 1.5 or 2 hours.

vii) Employment of relatives as attendants

Allowance	three people employed a relative on a regular basis, two paid a relative as a backup only
Service	one relative employed

viii) Expenditure on items other than attendant care

Allowance	minimal
Service	not possible

ix) Tasks performed by attendants

Allowance	principally personal care but often involved the integration of non personal care tasks; non personal care tasks sometimes done in lieu of personal care provided by a member of the household
Service	restricted at first to personal care only; some integration of other tasks later in pilot

x) Accumulation of unused hours

Allowance	yes
Service	yes

xi) 'Unauthorised' extra hours

Allowance	paid out of own pocket
Service	paid for by pilot in three cases

xii) Attendants Employed

No differences between attendants employed in the two models in terms of age, sex, marital status (slightly more single attendants in allowance model), numbers of dependents, dismissals and resignations, number of shifts and hours per week.

There *were* differences between attendants employed in the two models in terms of education (more nurses in the service model), previous contact with disabled people (much less in allowance model), how the job was found (more through advertisements in service model), having other jobs (although the proportion in each model having other jobs was similar, the proportion having other full time jobs was greater in the service model), and method of getting to work (more allowance attendants were within walking distance of participant's house).

xiii) Rates of Pay

Allowance	some, but not much variation in rates; rates per hour used for small numbers of attendants were $4 (juniors), $5, $7, $8, $10 (including travel)
Service	all paid Home Care Service award rates.

xix) Use of co-ordinator's time

Allowance	limited to matters related to cheques, insurance policies for participants; help in locating attendants (3 participants on isolated occasions); repeated support and help when household member less available than usual (one participant).
Service	by design, the Co-ordinator was required to involve herself in all aspects of attendant management and participant support.

xx) Participant's satisfaction

Allowance	very satisfied; participants previously dissatisfied with agency-provided service found managing an allowance gave them the level of control they required and presented no insurmountable difficulties. Two previously inexperienced people thought they would feel more secure with agency back up.
Service	very satisfied (the characteristics of this particular service model tried to maximise client control) but half would be just as satisfied to receive the allowance only.

It must be emphasised that it is not necessary to establish 'deficiencies' in either model as a means of justifying the need for the other. It is clear that there has been an expressed need for both. It is also possible that any given individual may prefer and/or need to use a different model at different stages of his life.

Section 6 Quality of Life

During the time attendant care was used

- desired changes in living arrangements occurred for eight people
- undesired changes in living arrangements were prevented for four people (when a previous carer was no longer available)
- 'marriages' were both made and broken
- minimal changes in employment status occurred
- self concept remained stable for both groups and individuals
- the percentage reporting dissatisfaction with health and personal care, relationships with relatives and close friends, sexual relationships, a course of study, understanding self, hobbies, active recreation and independence, decreased
- allowance groups 1 and 2 and the service group did not differ in terms of increase in satisfaction in important areas
- the observed decrease in dissatisfaction for the allowance groups (1 showing a greater decrease than 2) was not statistically significant.

- individual increases in satisfaction were reported by varying small numbers of people for physical and material well-being, relationships with relatives, understanding self, and independence

- people previously dissatisfied with care provided through a service agency found their control over care arrangements greatly increased when in receipt of an allowance

- two people experienced negative outcomes

- other household members living with some participants experienced improvements in their own lives

Section 7 Costs of Attendant Care

Costs have been considered for the specified group of the pilot study which was severely physically disabled adults, who were capable of and willing to obtain there own personal care. This target population had a severe personal care handicap such that at least two hours assistance per day was required for personal care. Persons within this category who do not have the intellectual capacity for managing their own affairs, although not excluded were not represented in the applications and were therefore not represented in the sample.

In the absence of paid or voluntary personal care in the community this group would be eligible to enter a nursing home which would attract government subsidy. Nine of the attendant care pilot participants had previously resided in deficit or state funded nursing homes for periods ranging from 2 to 7 years.

The pilot project has shown that a scheme sensitive to individual needs, need not prove as expensive in terms of unit costs as institutional services currently subsidised by government. At the same time, however, it is recognised that cost to government, for this group of people, would be greater if an attendant care scheme were introduced, because the majority do not in fact occupy nursing home places.

The pilot project enabled participants to buy the hours (level of service) they determined met their needs. These needs were seen to be influenced by a combination of factors including family/household arrangements and level of disability.

The literature expands on the debate that cash costs are not necessarily co-incident with resource costs and that cost should not be the only factor which determines the pattern of care. None of the participants in this study can survive without personal care assistance, it is a question of who should provide this care and whom the government should pay to provide it and how much.

An examination was made of cost to government had the participants been prepared to remain or live within institutions to which government had funding obligations. If these funding arrangements were reassessed to provide paid assistance for Attendant Care in the community the pilot project indicated that in the majority of cases care of the type provided by the attendant care pilot scheme is a less costly alternative to government than subsidy for that person in a nursing home. The services provided are governed by different structural constraints.

The numbers in the study were small and as such while indicating a range of needs, may limit the extent they may be taken as representative of the disabled population as a whole, in terms of physical dependence, family structure or socio-economic status. As in other studies we found that the pattern of household composition influenced the demand for paid services. Changes in the patterns of this composition and location may reduce the level of support available or desired. The pattern of Attendant Care Services available needed to be flexible and responsive to individual needs. The cost to government is diminished by the presence of unpaid assistance which substitutes for formal support services.

The cost to government could be higher if caring for the majority of study group member in institutions than if they were retained in the community receiving the support that would make this possible.

Section 8 Home Care Service of NSW Survey

1. Approximately 200* people aged between 16 and 65 years with a severe personal care handicap have been receiving personal care assistance from the Home Care Service of NSW in the Sydney Metropolitan area. Forty of them receive as many hours as the participants in the pilot study.

2. The service has been directly responsible for enabling people to leave institutions and has prevented the involuntary admission of others.

3. The service characteristics with respect to availability, coverage and client independence in aide management vary from branch to branch and will continue to do so despite management policies, until a complete regional management structure is established.

4. Hours of service may be limited to any one individual depending on competing needs.

5. Hours of service may be decreased due to increasing competing needs or reduction in budget allocation at state level.

6. Hours are not automatically transferred with a client who moves from one area to another.

7. Hours not used in a given week may not be transferred forward for later use.

8. Home Care Service of NSW and domiciliary nursing services are in some cases providing the same service on different days to the one household.

9. A degree of consumer control has been possible at some branches due to the election of clients with disability to the local management committee.

10. The majority of users interviewed were very satisfied with the service they were receiving and would prefer this mode of assistance rather than receiving an allowance. The dissatisfied clients were of the opinion that they did not require the services of an intermediary to arrange their own care but did require financial assistance to do so.

11. Updated information indicates that budget levels as at October 1985 have created waiting lists for service at many branches.

* the original number of 236 has been discounted by the rate indicated in the sample interviewed, to delete those incorrectly included.

Section 9 Potential Numbers

Estimates based on a number of different approaches would suggest that between 4,000 and 9,800 Australians would be eligible, in terms of this pilot project's eligibility criteria, for an attendant care scheme.

10.2 Participants' Preferences and Recommendations

The participants had an active role in the pilot scheme not only as members of a research study but also as individuals concerned with the introduction of a long term scheme. In addition to their own lobbying for such a meaure, many also submitted in oral, and/or written form their recommendations for inclusion in the report. Their preferences and recommendations reflected a range of ideas, opinions and options.

Participant AA

I would like to see a national scheme implemented along the lines of the Pilot Project with both the Allowance and Service Models.
I would see the people on the Allowance Model eventually receiving their Attendant Care hours as a component of a 'Disability Allowance' which would also include the Mobility Allowance and an allowance for purchasing aids and equipment.
The Service model would be operated by a central co-ordination unit with employment of attendants being handled through C.E.S. agencies in all States.
The central co-ordination unit could assist people on the Allowance Model if help is requested.

Participant BB

A continuation of the scheme as it is now available.
A personal care scheme which allows participants to decide when assistance is needed and the tasks which are to be included in the Attendant's duties.
A scheme where the hours are, within reason, organised around the disabled person.
A service model be maintained because its use is monitored.

Participant CC

Would like the continuation of Attendant Care as it allows the disabled person a high quality of life, no longer needing to feel the 'object of care' or a recipient of the welfare system.
An Attendant Care Scheme should allow the disabled person to; contribute to and be involved with the community, be fully employed and maintain an active social life, and be a consumer alongside his fellow man.
While acknowledging that any scheme would need periodic assessment, this would not necessitate setting up another structure , rather use an existing structure e.g. Rehabilitation Services and add another function to their services.
It should be a National Scheme administered and funded by the Commonwealth working towards ensuring uniformity of access and service delivery.
Attendant Care should not be included in the HACC programmes.
City participants in a scheme should be encouraged to look locally for attendants. There should however be consideration given to extra payments to those living in isolated areas.

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Participant DD

A scheme which allows choice. It is important to be able to decide 'who' the attendants will be and the time they work for the participants.
Shouldn't have to employ nurses or any medically oriented professional otherwise you are still getting into the institutional environment.
There needs to be the opportunity to employ several aides, to spread the work so you 'don't get sick of each other'
There should be a choice available of service or allowance. Some people might not want the responsibility of running their own allowance, it would be good to know that there was support staff there, that someone 'could' do it for you.
Attendant care should also include housework, otherwise too many people would become involved.

Participant EE

That an allowance be continued under the same conditions as in the pilot. This allowance model would not need a coordinator.
That it not be essential to move back to the Home Care Service model because no accumulation of hours is possible, hours could be reduced (to an unworkable level) if their budget was cut.
That paid attendants be non family members.

Participant FF

That a service model be retained as it offers security, I have needed and appreciated the assistance given by the coordinator.

Participant GG

That there be a continuation of both models though my personal preference is for an allowance.
That a National Scheme be introduced.
That each participant has control of their hours.
That each participant has the opportunity to choose and employ attendants.

Participant HH

That service models employ coordinators to offer assistance to consumers.
That allowance model people could use a service model for periods of time e.g. period of illness or increased disability.
That service models be offered for those who wish to undertake a training programme in attendant management.
That return to service mode should be at the request of the disabled person only.
That there be no travel payment in a metropolitan setting.

That a disability allowance be introduced with no accountability, but as a right by virtue of functional level.
That disabled people recognize their responsibilty to treat their attendants fairly.

Participant II

Would like to see attendant care allowance established on a nationwide basis.
Would like a scheme which gives a guaranteed number of hours.
Would like a scheme where the participant can choose their own attendants, so that personal things can be done to suit the individual. Training should be done by the disabled person.
Would prefer a scheme which allows the participants to arrange flexible rosters and avoid the situation where an attendant is having to go on to another client. It is important to have a situation where hours can be adjusted to suit the disabled person - not restricted to a timetable.
Would recommend that an allowance model be continued as the in pilot project where the cheque and advance payments has been a simple scheme to cope with.

Participant JJ

Would suggest that a range of services be available, including communal housing which provides accommodation for 3-4 residents. This should be available in both city and country areas. Care and company are available but the residents retain independence and control of their own lives.
Would see that care for the disabled should be retained in a manner which considers stages. It would be desirable to retain some institutions like Ferguson Lodge. They are needed for post hospital, elderly disabled or those without support or back up. I think there should be some time however when residents attempt an alternate form of care.
In the community there should be the choice of Allowance or service models of Attendant Care.
A new scheme is needed because current services available have short comings. The individual client has no 'right' to service and a clash of personalities between client and coordinator could lead to difficulties in hours made available or the attendants who are sent.
Would like to see a scheme where the coordinator doesn't have the ultimate control of hours and timing of service.

Participant KK

That a scheme be introduced in which an option is an allowance as it enables disabled people to live an independent life in individual accommodation if they wish.

Participant LL

Would like a scheme which offers the participant the choice of attendant staff and a say in how their work is to be done. This is in contrast to a nursing home where e.g. you may be subject to their prescribed method of bathing.
Would like the scheme to be National as the needs of disabled people are going to be similar State to State.
Disabled people should have the say in organizing what is going to happen to them.
The participants must have the opportunity to hire and fire their own staff, thus the disabled person is the "Boss of their own care".
Would prefer the option of an allowance as it was easy to administer.
The flexibility of an allowance gives the opportunity for participants to adjust the care to changes in their needs. They may be small but necessary.
There should be some avenue available for independent living training.
A coordinator could make people aware of services available.

Participant MM

Would like to see an allowance scheme introduced, its benefits being that the disabled person is;
able to hire his own attendants, "don't have to take stick from the people doing the hiring."
able to enjoy an employer/employee relationship; this control may not be available in a service model.
the hours can be arranged to suit the requirements of the disabled person i.e. not having to comply with available hours on a roster.
the potential is there to save/accumulate hours/money for the provision of extra hours as may be required in times of illness, change in routine, holidays
While not necessary for everyone as many have family living at home and other relatives and friends who would help, there should for the benefit of others be some structure which would have a pool of attendants available.
Attendant travel costs should be worked into conditions of employment.
If such conditions were unsatisfactory to the atttendants they should find something else. There should however be some consideration given to country areas e.g. population density would need to be taken into account.

Participant NN

Would suggest a scheme which offers community care. There must be choices of model available.
This scheme should be flexible to consider family members who do fill in, during an emergency situation where otherwise an attendant would have been called.
Services currently available are insufficient because they are term funded, there is 'uncertainty' with the number of hours allocated.
The individual needs to be in control to avoid "being told or advised what to do"...the professional back up staff should be just that -

called upon when YOU want.
The disabled person has to be involved and in control of funds allocated to him. These need to be dispersed on a permanent basis to maintain the level of independence he requires.
Recreation is a valid use of personal care; such activities are necessary to keep the person stable.
The disabled person should be able to decide what constitutes his/her personal care.

Participant OO

Prefers a scheme in which an allowance should be based on the level of need and recipients should not have to account for how they spent it. That while not favouring employing relatives for self would hold that others should not be barred from doing so if that is what they want.

Participant PP

Would like to see the continuation of a scheme similar to the pilot project. There should be the two models though if the service model was all that was offered that would be acceptable providing there was some guarantee of suitable and reliable staff. Times allocated need to be suited to the client rather than having to fit the service agency's requirements. Providing there is a guarantee of hours, the source of funding is of no concern.

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Appendix A

Information and Publicity

Organisations and Institutions Contacted or Visited

AGENCIES VISITED

(1) Royal North Shore Hospital

(2) Prince Henry Hospital

(3) Royal South Sydney Hospital

(4) Prince of Wales Hospital

(5) Mt Wilga Rehabilitation Centre

(6) Mt Druitt Hospital

(7) Royal Ryde Hospital

(8) Queen Elizabeth II Rehabilitation Centre

(9) Spastic Centre of N.S.W.

(10) Weemala

(11) Chesalon

(12) Ashton House

(13) Ferguson Lodge

(14) Australian Quadriplegic Association

(15) Paraplegic and Quadriplegic Association

(16) Voluntary Care Association of N.S.W.

(17) Handicapped Persons' Alliance

(18) Handicapped Persons' Bureau

(19) Sydney Home Nursing Service

(20) Western Metropolitan Department of Health

(21) Rockdale Mobile Nursing Unit

(22) Independent Living Centre

(23) Recreation and Organised Aid for Disabled

(24) Total Living Foundation

(25) Access Industries

(26) Royal Prince Alfred Hospital

(27) Royal Alexandra Hospital for Children

AGENCIES SENT INFORMATION/CONTACTED BY TELEPHONE

(1) Waverley War Memorial Hospital

(2) Eastern Suburbs Community Rehabilitation Team

(3) Mutliple Sclerosis Society

(4) Crippled Children's Society

(5) The Carer's Association of N.S.W.

(6) The Nursing Homes & Private Hospitals Association of Australia

(7) House with No Steps

(8) Disabilities Unlimited Association

(9) Red Cross Society

(10) Sutherland Hospital

(11) Lady Davidson Hospital

(12) Hornsby Hospital

(13) Regional Councils of Handicapped Persons' Alliance

(14) 39 Municipal and City councils

Newspapers and Journals Carrying Pilot Study Advertisements

NEWSPAPER ADVERTISING

Sydney Morning Herald
Auburn Review
Bankstown Torch
Blacktown District Star
Bondi Weekly Courier
Campbelltown District Star
Liverpool Champion
MacArthur Advertiser
Manly Daily
Mosman Daily
Mt Druitt District Star
Northern Standard
North Shore Advocate
Parramatta Mercury
Penrith District Star
St George & Sutherland Leader
Southern Courier
Wentworth Courier
Western Suburbs Courier

JOURNALS

Para-Quad News
Quadwrangle
Aware/YACS News
Link-Up
Breakthrough
The Key
Contact
Independence
Technical Aid to the Disabled

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HOME CARE SERVICE OF N.S.W.

ATTENDANT CARE PILOT STUDY

Using a grant made available by the Department of Social Security, the Home Care Service of N.S.W. is establishing a pilot scheme of Attendant Care for severely disabled people in the Sydney metropolitan area.

While only a small number of persons meeting the eligibility criteria will be selected to receive Attendant Care, or an allowance with which to purchase their own Attendant Care, the Home Care Service is interested in gathering information from all disabled persons in the Sydney metropolitan area who are currently receiving personal care assistance, or who feel that they are in need of Attendant Care. Special consideration will be given to those already in employment, or those contemplating employment or vocational training.

For the purposes of the pilot study the eligibility criteria have been specified as follows:

i) severely disabled;
ii) broad working age;
iii) medically stable;
iv) in need of between 2-4 hours assistance/day with personal care tasks such as bathing, toiletting, transferring and dressing;
v) at maximum level of independent functioning in their current environment.

If you are severely disabled, living in an institution or in the community, and wish to express interest in the program, please write to or phone

Ms Donna Percy
Co-ordinator,
Attendant Care Pilot Study
C/- Home Care Service of N.S.W.
P.O. Box A216
SOUTH SYDNEY, N.S.W. 2000
Ph. 217 7319

Closing date: 4th November, 1983.

Appendix B

Data Recording Forms

ATTENDANT CARE PROJECT : APPLICATION FORM

SURNAME: .... CHRISTIAN NAME(S): ....

ADDRESS: ....

.........................POSTCODE: ...... TELEPHONE NO: ....

HOW DID YOU FIND OUT ABOUT THIS PROJECT? ....

....

PLACE A TICK ☑ in the box beside the appropriate category.

1. DATE OF BIRTH: ..../..../....

2. SEX: 1 ☐ Male 2 ☐ Female

3. MARITAL STATUS:

1 ☐ Married/de facto	3 ☐ Separated
2 ☐ Divorced/widowed	4 ☐ Single

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4. NAME OF DISABLING CONDITION:

1 ☐ Spinal Cord Injury	6 ☐ Cerebral Palsy
2 ☐ Limb Injury/Amputee	7 ☐ Muscular Distrophy
3 ☐ Multiple Sclerosis	8 ☐ Polio
4 ☐ Stroke C.V.A.	9 ☐ Other: ....
5 ☐ Spina Bifida	....

5. HOW LONG AGO DID YOU BECOME DISABLED? ....YEARS

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6. DO YOU HAVE A PERSONAL CARE HANDICAP? 1 ☐ Yes 2 ☐ No

7. APPROXIMATELY HOW MANY HOURS OF PERSONAL CARE ASSISTANCE WOULD YOU NEED EVERY DAY? ....HOURS

8. CURRENT ATTENDANT CARE:

1 ☐ Partner	5 ☐ Volunteer attendant
2 ☐ Parent	6 ☐ District Nurse
3 ☐ Other relative	7 ☐ Hospital/Hostel/ Nursing Home Staff
4 ☐ Paid attendant	

.../2

9. CURRENT ACCOMMODATION:

1 ☐ Own Home
2 ☐ Family Home
3 ☐ Nursing Home
4 ☐ Hospital
5 ☐ Hostel
6 ☐ Group Home

10.

1 ☐ Unit/flat
2 ☐ House

11.

1 ☐ Own/Mortgage
2 ☐ Rent

12. If own home or family home, have you ever lived in an institution? 1 ☐ Yes 2 ☐ No

13. If nursing home, hospital, hostel or group home, how long have you been living in your present accommodation? ....Years

14. IF NOT LIVING IN AN INSTITUTION SHARE ACCOMMODATION WITH:

1 ☐ No-one
2 ☐ Spouse/partner (abled-bodied)
3 ☐ Spouse/Partner (disabled)
4 ☐ Children
5 ☐ Friend(s) (abled-bodied)
6 ☐ Friend(s) (disabled)
7 ☐ Housekeeper

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15. PROPOSED ACCOMMODATION:

If selected to participate in the Attendant Care Project do you intend to move into different accommodation? 1 ☐ Yes 2 ☐ No

If you DO INTEND TO MOVE:
16. To which area of Sydney? ....

17. Proposed type of dwelling: 1 ☐ Unit/flat
2 ☐ House

18. Proposed financing of dwelling: 1 ☐ Own/Mortgage
2 ☐ Rent

19. Propose to share accommodation with:

1 ☐ No-one
2 ☐ Spouse/partner (abled-bodied)
3 ☐ Spouse/partner (disabled)
4 ☐ Children
5 ☐ Friend(s) (abled-bodied)
6 ☐ Friend(s) (disabled)
7 ☐ Housekeeper

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20. HIGHEST LEVEL OF EDUCATION:

1 ☐ No School Certificate/Intermediate
2 ☐ School Certificate/Intermediate YEAR: ......
3 ☐ H.S.C./Leaving Certificate YEAR: ......
4 ☐ Tech. or CAE Certificate or Diploma YEAR: ......
5 ☐ University Degree or Equivalent YEAR: ......

.../3

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21. EMPLOYMENT:

☐ Employed
- 1 ☐ Sheltered Workshop - paid
- 2 ☐ Open employment - paid
- 3 ☐ Voluntary work
- 4 ☐ Studying, re-training, etc.

☐ Unemployed
- 5 ☐ By choice
- 6 ☐ Because of lack of skills (Cannot return to previous work)
- 7 ☐ Because discriminated against
- 8 ☐ Too few jobs available

22. IF EMPLOYED, OCCUPATION: ....

23. YOUR CURRENT INCOME:

1 ☐ Invalid Pension
2 ☐ Other Pension
3 ☐ Sickness Benefits
4 ☐ Wages/Salary
5 ☐ Worker's Compensation
6 ☐ Investment
7 ☐ No separate income

24. OTHER HOUSEHOLD INCOME:

1 ☐ Invalid Pension
2 ☐ Other Pension
3 ☐ Sickness Benefits
4 ☐ Wages/Salary
5 ☐ Worker's Compensation
6 ☐ Investment
7 ☐ No other incomes

25. IF UNEMPLOYED BUT WANT TO WORK, IN WHICH OCCUPATION WOULD YOU SEEK WORK?

....

26. IF UNEMPLOYED AND DO NOT WANT TO WORK OR CANNOT FIND WORK, WHAT DO YOU ANTICIPATE YOUR MAJOR "OCCUPATION" WILL BE IF SELECTED TO PARTICIPATE IN THE ATTENDANT CARE PILOT PROJECT?

....

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27. IF SELECTED TO PARTICIPATE IN THE ATTENDANT CARE PILOT PROJECT, WHICH METHOD WOULD YOU PREFER?

1 ☐ Receive money to employ own attendant(s)

2 ☐ Use attendant(s) employed by Home Care Service

Have you considered the building alterations and extra equipment that might be necessary if you are planning to move into different accommodation?

Do you want to nominate any particular person(s) to be your attendant(s)?

Certain skills are required by both disabled people and their attendants, to successfully commence and maintain attendant care arrangements. What skills do you think will be important and what training programs will be needed?

What, in your opinion, are the most important things about your life that you expect would improve if you had the services of paid attendant carers?

ATTENDANT CARE PILOT STUDY

ATTENDANT INFORMATION FORM

To be filled in by attendant on commencement of duties and forwarded in the pre-paid envelope provided to:

Attendant Care Project
Department of Community Medicine
Westmead Centre
P.O. Box 191, Wentworthville NSW 2145

The information requested on this form is for research purposes only and will be treated as CONFIDENTIAL. Information about an individual will not be made available to any other person or organisation. Your answers will help us to describe people who work as attendants and will allow us to see if there are any differences between those who find they like the work and stay on, and those who do not.

Please write your answers in the spaces provided or place a tick (✓) in the box beside the answer which describes you.

1. YOUR ATTENDANT NUMBER: ....

2. YOUR EMPLOYER'S NUMBER: ....

3. AGE:
   - 25 OR YOUNGER 1 ☐
   - 26 TO 45 2 ☐
   - 46 TO 65 3 ☐
   - 66 AND OLDER 4 ☐

4. MARITAL STATUS:
   - SINGLE 1 ☐
   - MARRIED 2 ☐
   - WIDOWED/SEPARATED/ DIVORCED 3 ☐

5. NUMBER OF DEPENDENTS: (not counting yourself)
   - NONE 1 ☐
   - ONE 2 ☐
   - TWO OR MORE 3 ☐

6. WHAT IS THE HIGHEST LEVEL OF EDUCATION YOU HAVE REACHED?
   - NO CERTIFICATE 1 ☐
   - SCHOOL CERTIFICATE (or Intermediate) 2 ☐
   - HIGHER SCHOOL CERTIFICATE (or Leaving) 3 ☐
   - TECHNICAL COLLEGE CERTIFICATE 4 ☐
   - NURSING CERTIFICATE 5 ☐
   - DIPLOMA OR DEGREE 6 ☐

.../2

7. HAVE YOU PREVIOUSLY HAD ANY CLOSE CONTACT WITH A PHYSICALLY DISABLED PERSON?

NO 1 ☐
A RELATIVE 2 ☐
AT WORK 3 ☐
OTHER 4 ☐

IF "OTHER" please describe: ....

....

8. HAVE YOU PREVIOUSLY WORKED AS AN ATTENDANT CARER?

YES 1 ☐
NO 2 ☐

IF "YES", for how many years? ....years

9. HOW DID YOU FIND OUT ABOUT THIS JOB?

ADVERTISEMENT 1 ☐
THROUGH A FRIEND 2 ☐
ALREADY KNEW EMPLOYER 3 ☐

10. AT THE PRESENT TIME, DO YOU HAVE ANY OTHER JOBS APART FROM THIS ONE?

NO 1 ☐
ANOTHER ATTENDANT CARE JOB 2 ☐
HOME CARE SERVICE AID 3 ☐
DOMESTIC DUTIES FOR OWN HOUSEHOLD 4 ☐
OTHER PART-TIME JOB 5 ☐
OTHER FULL-TIME JOB 6 ☐

11. APPROXIMATELY HOW FAR DO YOU TRAVEL TO YOUR EMPLOYER'S HOME?

.............Kms

12. HOW LONG DOES THIS JOURNEY TAKE?

.............minutes

13. WHAT IS YOUR USUAL METHOD OF TRAVEL?

WALK 1 ☐
PRIVATE CAR 2 ☐
TAXI 3 ☐
PUBLIC TRANSPORT 4 ☐
LIVE IN EMPLOYER'S HOME 5 ☐

14. HOW MANY HOURS PER WEEK DO YOU WORK FOR THIS EMPLOYER?

.............hours

.../3

15. WHAT TASK DO YOU CARRY OUT FOR THIS EMPLOYER?

TRANSFERS 1 ☐
SHOWERING/BATHING 2 ☐
TOILET DUTIES 3 ☐
DRESSING 4 ☐
OTHER 5 ☐

IF "OTHER" please list: ....
....
....
....

16. FILL IN YOUR STARTING AND FINISHING TIMES FOR EACH DAY OF THE WEEK ON WHICH YOU WORK FOR THIS EMPLOYER. IF YOUR WORK IS AT TWO OR MORE DIFFERENT TIMES ON THE ONE DAY PLEASE SHOW EACH STARTING AND FINISHING TIME.

DAY	STARTING TIME	FINISHING TIME	HOURS WORKED
MONDAY	1.		
	2.		
	3.		
TUESDAY	1.		
	2.		
	3.		
WEDNESDAY	1.		
	2.		
	3.		
THURSDAY	1.		
	2.		
	3.		
FRIDAY	1.		
	2.		
	3.		
SATURDAY	1.		
	2.		
	3.		
SUNDAY	1.		
	2.		
	3.		

Thank you for taking the time to answer the questions. Please check (now) that all questions have been answered before placing form in the pre-paid envelope and posting it to the Attendant Care Project.

ATTENDANT CARE PILOT STUDY

NOTIFICATION OF RESIGNATION OR DISMISSAL OF AN ATTENDANT

To be filled in by the employer (or client, if attendant supplied by Home Care Service) when an attendant ceases to be employed in your home. Please return completed form in pre-paid envelope supplied to:

Attendant Care Project
Department of Community Medicine
Westmead Centre
P.O. Box 191, Wentworthville NSW 2145

The information requested on this form is for research purposes only and will be treated as CONFIDENTIAL. Information about an individual will not be made available to any other person or organisation. Your answers will help us to describe people who work as attendants and will allow us to see if there are any differences between those who find they like the work and stay on, and those who do not.

Please write your answers in the spaces provided or place a tick (✓) in the box beside the answer which describes you.

1. THE ATTENDANT'S NUMBER: ....

2. YOUR PARTICIPANT NUMBER: ....

3. DATE ATTENDANT COMMENCED WORKING FOR YOU: .../.../...

4. DATE ATTENDANT CEASED WORKING FOR YOU: .../.../...

5. ATTENDANT: RESIGNED ☐
   WAS DISMISSED ☐

6. IF ATTENDANT RESIGNED WHAT, IF ANY, REASONS WERE GIVEN?

....

....

....

....

....

....

....

....

.../2

7. IF ATTENDANT WAS DISMISSED, WHY?

....

....

....

....

....

....

....

....

The research group would like to interview the attendant about some aspects of working as an attendant.

8. DO YOU GIVE YOUR PERMISSION FOR THE RESEARCH GROUP TO INTERVIEW THE ATTENDANT?

YES ☐

NO ☐

9. DOES THE ATTENDANT AGREE TO BE INTERVIEWED BY THE RESEARCH GROUP?

YES ☐

NO ☐

10. IF THE ANSWERS TO THE ABOVE TWO QUESTIONS WERE "YES", FILL IN THE NAME AND TELEPHONE NUMBER OF THE ATTENDANT:

NAME OF ATTENDANT: ....

TELEPHONE NUMBER: ....

Thank you for taking the time to answer these questions. Please check now that all questions have been answered before placing this form in the envelope provided and posting it to the Attendant Care Project.

ATTENDANT CARE PROJECT

Expenditure for week ending:_____/______/______

Participant Number:__________________________

Attendants	Personal Care (Hrs)	Other Tasks (Hours) *	Total Hours	Rate	Amount Paid
1:__					
2:__					
3:__					
4:__					
5:__					
6:__					
TOTALS:					

OTHER EXPENDITURE:

Item	Amount
TOTAL "OTHER"	
TOTAL EXPENDITURE	

* What other tasks apart from personal care were Attendants paid to do?

____

____

____

____

____

Attendant Care Pilot Project

Occupational Therapy Assessment Summary

Name:...

Address:..

Phone: Home -...................

Work -...................

Outline of Abilities:...

....

....

Accommodation/Social Situations:....................................

....

....

Employment:...

....

Independent Funtioning:...

....

....

General Health:...

....

Social Supports/Contacts:...

....

....

Equipment/home modifications/learning suggested:....................

....

....

...2/

Aims/Objectives as part of project:...................................
....
....

Other Aims/Objectives:..
....
....

Attendant Requirements: Time/Comments

☐ Feeding:..
☐ Showering:..
☐ Dressing:...
☐ Bowel Management:...
☐ Urinary Management:...
☐ Grooming:...
☐ Hygiene/Health:...
☐ Skin Care:..
☐ Transfers/posture/turning:..
☐ Driving:..
☐ Communication:..
☐
☐
☐

Proposed time/routine:..
....

Recommendations:..
....
....

AMENDED-1

ATTENDANT CARE PILOT STUDY

INFORMATION SUPPLIED BY SYDNEY METROPOLITAN BRANCH CO-ORDINATORS OF THE HOME CARE SERVICE OF N.S.W.

BRANCH: ______________________________ DATE FORM COMPLETED: / / 1984

1. TOTAL NUMBER OF PERSONAL CARE CLIENTS:
   ☐ 65 and over
   ☐ under 65 and over 16

2. WAITING LIST FOR PERSONAL CARE SERVICE:
   ☐ 65 and over
   ☐ under 65 and over 16

3. NAME OF PERSON IN YOUR AREA WHO WOULD HAVE THE MOST INFORMATION ABOUT PHYSICALLY DISABLED PEOPLE IN THE AREA:
   NAME: ______________________________
   POSITION: ______________________________ TELEPHONE: ______________

4. WHO INTERVIEWS/SELECTS PERSONAL CARE AIDES?

5. WHO TRAINS THE PERSONAL CARE AIDES?

6. WHAT ADDITIONAL SERVICES DO DISABLED CLIENTS NEED?

7. WHAT ARE THE BIGGEST PROBLEMS YOU ENCOUNTER IN CO-ORDINATING A PERSONAL CARE SERVICE FOR THE DISABLED?

.../2

8. ARE ANY OF THE PEOPLE REFERRED TO THE BRANCH FOR PERSONAL CARE ASSISTANCE, ASSESSED AS BEING INELIGIBLE?

☐ ☐ 1. YES

☐ ☐ 2. NO

☐ ☐ 3. APPROXIMATELY HOW MANY SINCE AUGUST 1983?

16-65 65+

IF YES, GIVE EXAMPLES:

----

9. ARE THERE ARE PEOPLE WITH A PERSONAL CARE HANDICAP WHO ARE REFERRED TO THE BRANCH, ASSESSED AS ELIGIBLE AND WHO THEN REFUSE THE SERVICE?

☐ ☐ 1. YES

☐ ☐ 2. NO

☐ ☐ 3. APPROXIMATELY HOW MANY SINCE AUGUST 1983?

16-65 65+

WHY DO YOU THINK THIS IS?

REASON	VERY IMPORTANT	SOME IMPORTANCE	NOT IMPORTANT
Inability to pay fees			
See the service as a charity			
Do not think they need it			
Do not want strangers in the home			
Do not want strangers doing such personal tasks			
Want to remain independent			

10. DOES THE BRANCH ACTIVELY SEEK OUT PEOPLE IN THE AREA WHO MAY NEED PERSONAL CARE ASSISTANCE?

☐ 1. YES

☐ 2. NO

IF YES, HOW?

----

11. ARE THERE ANY OTHER ORGANISATIONS IN YOUR AREA WHICH PROVIDE PERSONAL CARE ASSISTANCE TO DISABLED PEOPLE?

AMENDED/1

ATTENDANT CARE PILOT STUDY

SURVEY OF CLIENTS OF SYDNEY METROPOLITAN BRANCHES OF HOME CARE SERVICE OF NSW (BETWEEN THE AGES OF 16 & 65) WITH A PERSONAL CARE HANDICAP

Complete one form for each client with a personal care handicap, whether or not receiving personal care assistance from HCS.

BRANCH: ________________________________ CLIENT NUMBER: ____________________________

1. SEX:
   - ☐ MALE
   - ☐ FEMALE

2. LIVES:
   - ☐ ALONE
   - ☐ WITH OTHER DISABLED PERSON ONLY
   - ☐ WITH AT LEAST ONE ABLE-BODIED PERSON

3. DISABLING CONDITION:
   - ☐ SPINAL INJURY
   - ☐ POST POLIO
   - ☐ MS
   - ☐ MUSCULAR DYSTROPHY
   - ☐ CEREBRAL PALSY
   - ☐ MUSCULAR ATROPHY
   - ☐ OTHER

4. EMPLOYED:
   - ☐ FULL TIME
   - ☐ PART TIME
   - ☐ NO

5. ASSISTANCE FROM SOMEONE REQUIRED FOR PERSONAL CARE TASKS:
   - ☐ YES
   - ☐ NO

6. TOTAL HRS/WEEK PERSONAL CARE NEEDED: ____

7. HRS/WEEK PERSONAL CARE BY HCS: ____

8. REASON IF HCS NOT PROVIDING TOTAL HOURS NEEDED:
   - ☐ Not requested because household members provide assistance
   - ☐ Not requested because another organisation provides assistance
   - ☐ Not requested because client organises alternative assistance
   - ☐ Branch has insufficient hours

9. NAMES OF ANY OTHER AGENCIES OR ORGANISATIONS PROVIDING ANY PERSONAL CARE:

   ____

10. HOUSEKEEPING ASSISTANCE BY HCS: ______________________________ (HRS/WEEK)

11. COST/HOUR (TO THE CLIENT) OF HCS HOURS ____

IF RECEIVING PERSONAL CARE SERVICE FROM HCS:

12. DATE COMMENCED SERVICE: ... .../... 13. NO. OF ATTENDANTS IN ANY ONE WEEK: ----------

14. TASKS PERFORMED BY ATTENDANTS:

☐ bathing/showering
☐ dressing
urinary/bowel:
☐ -catheterisation
☐ -enemas
☐ -manual evacuation
☐ -toilet
☐ grooming
☐ feeding
☐ transport
☐ ---------------------
☐ ---------------------
☐ ---------------------
☐ --------------------
☐ --------------------

15. PATTERN OF DELIVERY OF SERVICE (e.g. 3 mornings for 3 hrs; 7 evenings for 1 hr):

----

16. NUMBER OF RESIGNATIONS/DISMISSALS OF ATTENDANTS WORKING WITH THIS PERSON (specify over what period of time) e.g. 10 in 3 months:

----

17. BACK UP LIST OF AIDES KEPT BY CO-ORDINATOR:

☐ YES
☐ NO

18. BACK UP LIST OF AIDES IN HANDS OF CLIENT:

☐ YES
☐ NO

ATTENDANT CARE PILOT STUDY

HOME CARE SERVICE OF NSW PERSONAL CARE CLIENTS INTERVIEW

BRANCH:____________ CLIENT NO:_______ DATE:______

1. **All personal care assistance** (paid and voluntary)

For each person who assists regularly indicate HCS/DN/HOUSEHOLD MEMBER/OTHER RELATIVE/NEIGHBOUR/OTHER FRIEND/OTHER AGENCY
Include assistance at home and at work/study, etc.

PERSON	CATEGORY	HOURS/WEEK	PAID	UNPAID
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
TOTAL				

2. a) Are you getting as many hours from HCS as you asked for?

☐ YES

☐ NO

b) Are you getting as many hours from HCS as you would like?

☐ YES

☐ NO

If NO to either of above questions, why not? ____________________

____

____

____

When was the last assessment of hours? ____________________

3. Who does the housework (washing, cleaning, ironing, cooking, etc)?

		HOURS/WEEK	PAID/HOUR
Self	☐	________	________
Home Care Service	☐	________	________
Household Members	☐	________	________
Non-resident Relatives	☐	________	________
Neighbours	☐	________	________
Friends	☐	________	________
Other	☐	________	________

(Tick more that one if necessary)

4. What personal care tasks do HCS aides do for you? ____________________

____

____

____

____

____

5. What do you pay the HCS?

____

6. What aspects of HCS personal care are very good? ____________________

____

____

____

____

7. What aspects of HCS personal care are you unhappy about? ______________

____

____

____

____

8. I am interested in how much control you feel you have in the organisation of your HCS personal care. With this in mind please comment on the following:

a) selection of aides

b) training of aides

c) when aides come

d) what aides do for you

e) back up arrangements

f) replacement of aides

9. What changes would you suggest for improving the service?

10. Would you prefer another way of obtaining/organising your personal care?

11. When did you commence using the service? ______________________

12. What were your arrangements prior to commencement of the service?

13. How did you first hear about/become involved with HCS personal care?

14. What improvements in your life do you feel are due to your getting personal care assistance?

ATTENDANT CARE PROJECT

INDICATORS OF QUALITY OF LIFE

PARTICIPANT NUMBER: ....

DATE FORM COMPLETED: .../.../...

---

1. Consider your present living arrangements and decide which of the five descriptions below, best describes your situation.

1 ☐
- . I live in my own home (alone, with spouse or significant other OR with friends of choice).
- . The required building alterations have been done and the necessary special equipment obtained.
- . I have a considerable say in day to day decision making.
- . My personal care needs are met how and when I choose.

2 ☐
- . I live in my own home (alone, with spouse or significant other OR with friends of choice).
- . Some of the required building alterations have not been done.
- . I do not have as much say as I would like in day to day decision making.
- . My personal care needs are not really being met in the way and at the time I would choose.

3 ☐
- . I live in someone else's home, e.g., parent, brother, sister, son, daugther, grandparents, uncle, aunt.
- . The required building alterations have been done and the necessary special equipment obtained.
- . The person who owns the home assumes the right to make most of the day to day decisions.
- . My personal care needs are met how and when I choose.

4 ☐
- . I live in someone else's home, e.g., parent, brother, sister, son, daugther, grandparents, uncle, aunt.
- . Some of the required building alterations have not been done.
- . The person who owns the home assumes the right to make most of the day to day decisions.
- . My personal care needs are not really being met in the way and at the time I would choose.

5 ☐
- . I live in a hospital, nursing home or hostel.
- . I do not have much say in the day to day decision making, where I live.
- . My personal care needs are not really being met in the way and at the time I would choose.

.../2

2. The following items are different components of life. Indicate how important each component is to you in your life.

	1. Very Important	2. Moderately Important	3. Not at all Important
PHYSICAL AND MATERIAL WELL BEING			
1. home modified to suit your present physical condition, desirable food, security, transport	☐	☐	☐
2. health and personal care	☐	☐	☐
RELATIONSHIPS WITH OTHER PEOPLE			
3. relatives	☐	☐	☐
4. sexual relationship	☐	☐	☐
5. having and rearing children	☐	☐	☐
6. close friends	☐	☐	☐
COMMUNITY AND CIVIC ACTIVITIES			
7. helping others	☐	☐	☐
8. belonging to groups, organisations, clubs	☐	☐	☐
PERSONAL DEVELOPMENT			
9. a course of study, teaching yourself new things	☐	☐	☐
10. understanding yourself (your strengths and limitations)	☐	☐	☐
11. work (paid or voluntary) that is interesting and rewarding	☐	☐	☐
12. hobbies that allow you to be creative	☐	☐	☐
RECREATION			
13. socialising with others	☐	☐	☐
14. watching sport, films, plays, music, reading	☐	☐	☐
15. active games and sports (indoor or outdoor)	☐	☐	☐
INDEPENDENCE			
16. make my own decisions about when I do things	☐	☐	☐
17. run my own household	☐	☐	☐
18. live with people with whom I choose to live (or alone if I wish)	☐	☐	☐

.../3

3. We each experience needs and wants in relation to each of these components of life. Indicate how satisfied you are, at the present time, with the extent to which your needs and wants are being met in respect of each of the items listed.

	1. Very Well Met	2. Moderately Well Met	3. Not at all Well Met
PHYSICAL AND MATERIAL WELL BEING			
1. home modified to suit your present physical condition, desirable food, security, transport	☐	☐	☐
2. health and personal care	☐	☐	☐
RELATIONSHIPS WITH OTHER PEOPLE			
3. relatives	☐	☐	☐
4. sexual relationship	☐	☐	☐
5. having and rearing children	☐	☐	☐
6. close friends	☐	☐	☐
COMMUNITY AND CIVIC ACTIVITIES			
7. helping others	☐	☐	☐
8. belonging to groups, organisations, clubs	☐	☐	☐
PERSONAL DEVELOPMENT			
9. a course of study, teaching yourself new things	☐	☐	☐
10. understanding yourself (your strengths and limitations)	☐	☐	☐
11. work (paid or voluntary) that is interesting and rewarding	☐	☐	☐
12. hobbies that allow you to be creative	☐	☐	☐
RECREATION			
13. socialising with others	☐	☐	☐
14. watching sport, films, plays, music, reading	☐	☐	☐
15. active games and sports (indoor or outdoor)	☐	☐	☐
INDEPENDENCE			
16. make my own decisions about when I do things	☐	☐	☐
17. run my own household	☐	☐	☐
18. live with people with whom I choose to live (or alone if I wish)	☐	☐	☐

.../4

4. Here are some statements you could use to describe how you feel about yourself. Please read each statement carefully and place a tick ☑ in the box that best fits how the statement describes you.

Answer each item as best you can. Remember there are no right or wrong answers.

	Describes Me Exactly		Somewhat Describes Me		Doesn't Describe Me At All
1. I am a pleasant person	☐	☐	☐	☐	☐
2. I do not feel useful	☐	☐	☐	☐	☐
3. I get on well with members of the opposite sex.	☐	☐	☐	☐	☐
4. My family does not understand me	☐	☐	☐	☐	☐
5. I like who I am	☐	☐	☐	☐	☐
6. I feel hopeful about the future	☐	☐	☐	☐	☐
7. I have difficulty making decisions	☐	☐	☐	☐	☐
8. I like meeting new people	☐	☐	☐	☐	☐
9. I am not an easy person to get along with	☐	☐	☐	☐	☐
10. I am a failure at everything I try to do	☐	☐	☐	☐	☐
11. I give up too easily	☐	☐	☐	☐	☐
12. I am not as smart as most people	☐	☐	☐	☐	☐
13. I have difficulty concentrating	☐	☐	☐	☐	☐
14. I am satisfied with my sexual relationships	☐	☐	☐	☐	☐
15. I am happy with my family relationships	☐	☐	☐	☐	☐
16. I do not treat other people well	☐	☐	☐	☐	☐
17. I am comfortable being around people	☐	☐	☐	☐	☐

ATTENDANT CARE PILOT PROJECT

HOUSEHOLD MEMBERS' QUESTIONS

Date....................

Relationship to Participant....................

1. What personal care tasks did you perform before the Attendant Care Pilot started?
How much time did it require from you?

....

....

....

....

....

....

2. What personal care tasks do you still do now?
How much time does this require from you each week?

....

....

....

....

....

....

3. How has the ACP affected your independence and quality of life?

....

....

....

....

....

....

2/....
(over)

4. How do you think the ACP has affected the independence and quality of life of life of the participant in your household?

....
....
....
....
....
....

5. What aspects of the ACP are you happy with?

....
....
....
....
....
....

6. What aspects of the ACP are you unhappy with?

....
....
....
....
....
....

Note: Data from selected items only included in the report.

EXTRA COSTS OF DISABLED LIVING INTERVIEW SCHEDULE*

SUBURB:................

ACP NUMBER: ....

HCS SAMPLE: ....

PVTE SAMPLE:...........

A. DISABILITY

1. How long ago did you start using a wheelchair?

No. of years ago:.............

That would be since 19...........

2. What was the cause of your disability?

....

....

....

3. Which parts of your body are affected?

Arm(s)	1
Leg(s)	2
Arm(s) and Leg(s)	3

4. Over the next two years do you expect the extent of your handicap to:

Increase	1
Decrease	2
Stay much the same	3

5. Do you have any other problems with your health?

....

....

....

....

....

....

....

....

....

*** Adapted from Hyman, M. The Extra Costs of Disabled Living, 1977.**

B. SPECIAL EQUIPMENT

You may have purchased some of the following items more than once during the time you have been disabled. The information is requested for the most recent time each item was purchased.

6.

Item	Cost	Year Purchased	Who Paid	If replacement, how many years since previous one purchased.
wheelchair 1				
wheelchair 2				
tripod/crutches				
pick-up stick				
commode				
shower chair				
special bed				
special mattress				
special table				
urinary equipment				
hoist-bed				
hoist-bath/toilet				
car conversion				
______________				
______________				
______________				
______________				
______________				

7. How much was spent over the past twelve months on repair and maintenance of any special items of equipment?

$.............

Who paid?

....

.../3

C. PERSONAL CARE

8. How do you manage to:

	No Difficulty	Difficulty but Independent	Difficulty & Dependent
a) Get in & out of bed	0	2	3
b) Get to or use toilet	0	4	6
c) Have bath or overall wash	0	2	3
d) Wash hands & face	0	2	3
e) Put on shoes/socks	0	2	3
f) Fasten buttons/zips	0	4	6
g) Dress - other than buttons, zips, shoes	0	2	3
h) Feed yourself	0	4	6
i) Comb hair (F) or shave (M)	0	2	3

TOTAL SCORE: ________

9. How long do you usually take to get dressed and ready for the day?

a) 'minimum tasks' day .... hours

b) 'maximum tasks' day .... hours

10. How long does someone else take to help you do this?

a) 'minimum tasks' day .... hours

b) 'maximum tasks' day .... hours

11. Who usually helps?

Relatives/friends living in same house as yourself	1
Other relatives/friends	2
Neighbour	3
Govt subsidised nursing	4
Home Care Service aide	5
Private nurse	6
Privately paid assistant	7

12. If help is paid for

Who pays? ....

How much per week? $............

13. How much assistance with personal care is required at other times of the day?

.... hours

.../4

14. Who usually helps?

Relatives/friends living in same house as yourself	1
Other relatives/friends	2
Neighbour	3
Govt subsidised nursing	4
Home Care Service aide	5
Private nurse	6
Privately paid assistant	7

15. If help is paid for

Who pays? ....

How much per week? $.....

16. Which of the following cost more than usual because you are disabled?

Hairdressing	1
Dentist	2
General Practitioner	3
Shopping for clothing	4

Estimate of how much more per year $.....

D. HOUSING

17. Alterations indoors	Cost	Year	Who Paid
Ramps			
Railings			
Door widening			
Switches/handles lowered			
Kitchen			
Bathroom			
Additions			
Other:..........			
....			
....			
....			

18. Alterations outdoors

Ramps
Railings
Pathways
Garage/Carport

Other:........

....

....

....

.../5

19. Running costs:

(a) What increases in running costs are you aware of that arise directly from your disability?

Electricity	....
Gas	....
Telephone	....
....	....
....	....
....	....

(b) Do you pay for jobs to be done that average householders would do themselves?

	Cost/Week	From an Organisation?
Car cleaning		
Car maintenance		
Gardening		
Handyman tasks		
House cleaning		
Washing/ironing		
Shopping		
Other:		
....		
....		

F. FOOD

20. Do you buy more expensive food, e.g., take aways or prepared frozen/canned foods because your disability limits the cooking you can do?

yes	1
no	2

estimate of extra spent $.....

.../6

G. CLOTHING

21. Do you have clothing specially made for you?

yes	1
no	2
estimate of extra cost (compared to ready made comparable items)	$.....

22. Does ready made clothing have to be altered to fit you because of your disability?

yes	1
no	2
cost	$....
OR hours spent voluntarily	.....hrs

23. Do your clothes require more frequent mending as a result of your disability?

yes	1
no	2
cost	$....
OR hours spent	.....hrs

H. INSURANCE

24. Have you ever had difficulty in buying life insurance?

no	1
never tried	2
already insured before disability	3
yes	4
extra cost?	$....

25. Have you ever had difficulty in buying health insurance?

no	1
never tried	2
yes	3

Details:..

....

....

....

.../7

I. PHARMACEUTICAL SUPPLIES

26.

Regularly used items	Cost to you per year	Who else contributes to cost?
....		
....		
....		
....		
....		
....		
....		
....		
....		
....		
....		

J. CAR

27. Did your disability affect the choice of car?

yes 1

no 2

In what ways? ....

....

....

28. What was the price differential?

	Year	Cost
car purchased		
car would have purchased		

29. What are the differences in running costs over a year?

$......

.../8

K. INCOME

30. i)	Earnings from employment	$
ii)	Earnings from self-employment	$
iii)	Non DSS pension (or superannuation) specify type:.....................	$
iv)	Interest	$
v)	Dividends	$
vi)	Income from rent	$
vii)	Allowance from family or friends	$
viii)	State Benefits:	
	a) Invalid pension	$
	b) SEA	$
	c) Supporting parent	$
	d) DNCB	$
	e) Mobility	$
	f) Spouse carer	$
	g) Unemployment	$
	h) Sickness	$
	i)	$
	j)	$
	k)	$
	l)	$
	m)	$

Do you have any other sources of income that I have not mentioned so far?

....

....

....

....

....

.../9

31. To what extent are your living expenses reduced by sharing the costs with other people living in the same household?

	Total Cost	Rebate	Your share
Rent			
Mortgage			
Council Rates			
Water Rates			
Electricity			
Gas			
Telephone			
Housekeeper			
Food			
House Insurance			
Car Expenses			
....			
....			
....			
....			
....			

32. Have you ever received compensation from any source as a result of your disability?

Year 19....

Source ....

Amount $.....

Attendant Care Pilot Study
Final Interview

Number: ____________
Date: ____________

Since commencing with the ACP

1a) How many times were you admitted to Hospital? ____________

b) How many days altogether did you spend in hospital? ____________

2a) How many times did you enter a nursing home? ____________

b) respite care? ____________

c) How many days altogether did you spend in a Nursing Home? ____________

3a) How many holidays have you had? ____________

b) How many days altogether on holidays? ____________

c) Did you use paid attendant care when on holidays? ____________

Current employment

4a) Full Employment ____________
Part time
N/A

b) Open
Sheltered
Student
Voluntary
Unemployed

Current marital status:-

5 Single
(live with) "significant other"
Widowed / Separated / Divorced

Current Living Arrangement:-

6. Parents/relatives
Significant other
Friends
Alone

7. Number of persons in household

8 Does anyone receive DNCB on account of you?

9 Ex HCS PC clients;-

For how many months did you use HCS PC ?

How many hours/week?

10. Do you currently HCS hours?
How many hours?

11. Do you plan to continue using some form of paid attendant care after the pilot finishes?

12. What is the current balance of your "Attendant Care Account" i.e. after last payment of attendants and before next cheque from coordinator.

13. Have you spent any attendant care allowanace on items other than wages and travel reimbursement?

Details	Item	Cost

14. What gaps, if any did you have between one attendant leaving and a replacement starting?

15. Do you have unmet needs because the attendant hours are insufficient?

16. What use have you made of the Coordinator's services?

Payment ______________________________

Assessment ______________________________

Other ______________________________

17. Have you been accommodated in Hospitals or Nursing Homes:-

Aged 0-16? __________ List periods ____________________

Aged 16+ __________ List periods ____________________

____

____

Future Personal Care

18. How many hours per week will you be seeking? ____________________

PC ____________________

House work ____________________

Handyman tasks ____________________

19. If the choice was offered would you employ a family member?

20. How would you feel about receiving an allowance even if this meant no support staff would be made available?

ATTENDANT CARE PILOT STUDY : ALLOWANCE MODEL TIMESHEET

PARTICIPANT NUMBER: A___ WEEK ENDING: / /85

DAY	ATTENDANT (NAMES OR NUMBER)	START TIME	FINISH TIME	HOURS WORKED	RATE OF PAY	TRAVEL PAID FOR (KMS)	OR FARES	RATE OF PAY FOR TRAVEL	ATTENDANT'S SIGNATURE
MONDAY					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
TUESDAY					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
WEDNESDAY					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
THURSDAY					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
FRIDAY					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
SATURDAY					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
SUNDAY					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	
					$ /hr			¢/km	

Participant's Signature

I confirm that the above information is correct.

HOME CARE SERVICE OF N.S.W.

ATTENDANT CARE PILOT STUDY

PAYMENT NO.: ....

DATE: .../.../....

NAME: ....

NO. HOURS PER WEEK: .... hrs

RATE: $

TRAVEL: $

DEDUCTIONS/EXTRAS: $

THIS PAYMENT: $______

COVERING PERSONAL CARE FROM .../.../...

TO .../.../...

METHOD OF PAYMENT:

CHEQUE ☐

TRANSFER TO CHEQUE ACCT. ☐

DATE OF NEXT PAYMENT: .../.../...

ABILITY PROFILE (MODIFIED)

APPLIANCE USED - BLADDER

QUESTION: 1 (A)

A - Not used.
B - Pads worn for outings and night.
C - Pads and/or protective pants at all times.
D - Intermittent catheter.
E - Catheter and bag.
F - Urinal - uredome with bag.
G - Commode wheelchair.

BLADDER CONTINENCE

Score if answer to 1 (A) is A or B

(B)

A - Normal control of bladder - never incontinent, no medication to achieve this.
B - May have some bladder urgency, hesitancy or frequency, but not greater than two hourly, non offensive in odour or hygiene. May need medication.
C - May have occasional accident but not more than on a weekly basis.
D - Frequent wetting due to incontinence.

BLADDER CONTINENCE

Score if answer to 1 (A) is C,D,E,F OR G

(C)

A - Independent of all care (except e.g. indwelling catheter change and not more than every fortnight), almost never (3 months) wet.
B - As for "A" above, but may need assistance with device changes but not more than twice weekly; i.e. visiting nurse or similar; non offensive in ordour or hygiene; independent in emptying collecting device.
C - May need assistance more than in answer "B" with equipment including catheterisation. Accidents occur, but less than once a week.
D - Despite aids, is frequently wet or offensive in odour.

BOWEL CONTINENCE

QUESTION: 2

A - Normal voluntary and effective control of bowels (never incontinent).
B - May have some bowel urgency but never any incontinence. There is some irregularity of

bowel habit, either excessive frequency or severe constipation. May require regular medication, but does not require any assistance with this.

C - Another person is required to help in maintaining an excretion pattern or else the individual has occasional sphincter accidents less than once a week.

D - More frequent soiling than answer "C" above.

DRESS UPPER BODY - DRESS LOWER BODY

QUESTIONS: 3 Bra, slip, pull-over and front opening garment etc.
4 Underpants, slacks, skirt, belt, pantyhose, shoes and laces etc.

Score each question separately from the following:

A - Intact: Able to dress upper (Q. 3) or lower (Q. 4) body including obtaining clothes from their customary places, able to manage zips, buttons, press-studs etc.

B - Limited: Requires prior retreival or arrangement of clothes or is able to dress presentably in spite of omission of some of the above.

or Requires use of special fasteners in clothing or for shoes.

or Takes more than a reasonable time.

C - Helper: Gives some useful assistance to a necessary helper.

D - Null: Unable to assist (Complete assistance given).

E - N/A: Dressing is not performed.

GROOMING

QUESTION: 5

A - Intact: Able to clean teeth or dentures, comb and brush hair, shave, apply make-up, including all preparations.

B - Limited: As above but requires adaptive or assistive device or takes more than reasonable time.

C - Helper: Assistance, supervision or cueing given for activity.

D - Null: Unable to perform grooming activities. Complete assistance given.

CARE OF PERINEUM/CLOTHING AT TOILET

QUESTION: 6

A - Intact: Able to cleanse self after voiding or bowel evacuation. Able to adjust clothing after using toilet. Able to put on/insert sanitary napkins/tampons.

B - Limited: Able to perform the above with some difficulty, with adaptive equipment, or takes more than a reasonable time but without assistance.

C - Helper: Needs assistance in adjusting clothes, using toilet paper or in personal hygiene. Does not require a full-time attendant for the entire process.

BATH OR SHOWER

QUESTION: 7

A - Intact: Able to wash and dry entire body including all preparations for bathing and showering.

B - Limited: As above but requires an adaptive or assistive device or takes more than a reasonable time.

C - Helper: Assistance, supervision, cueing or coaxing given in washing, drying and inspecting skin of body.

D - Null: Unable to wash, dry or inspect skin of body. Complete assistance necessary.

DRINK FROM CUP

QUESTION: 8

A - Intact: Able to drink from a cup at a tray and able to e.g. pour a cup of tea or otherwise simply dispense a drink for themselves.

B - Limited: Requires prior preparation such as liquid being poured, an adaptive or assistive device (e.g. a straw) or takes more than a reasonable time.

C - Helper: Another person is involved in the activity. Supervision, cueing, coaxing or physical assistance necessary to some degree.

D - Null: Unable to take fluid by mouth or has gross swallowing difficulty with spillage.

EAT FROM A PLATE

QUESTION: 9

A - Intact: Able to eat from a plate on a tray or table as normally prepared. Able to cut meat and butter bread.

B - Limited: Requires prior preparation such as meat being cut or bread buttered. needs adaptive device, e.g. rocking knife etc., or takes more than a reasonable time. Copes with getting food to mouth without assistance.

C - Helper: Able to take full meals by mouth (chew & swallow) but needs another's presence during a meal. Does not however require the uninterrupted attendence of an assistant.

D - Null: Cannot take normal meals by mouth (requiring e.g. prior food vitamisation), or has profound difficulty in chewing & swallowing with regurgitation or cannot be left alone at all during meals.

DON BRACE OR PROSTHESIS

QUESTION: 10

A - Intact: Does not have brace or prosthesis.

B - Limited: Able to don prescribed sling, splint, brace, corset or prosthesis with reasonable ease.

C - Helper: Able to don prescribed sling, splint, brace, corset or prosthesis but with difficulty, or in more than a reasonable time.

D - Null: Needs partial or complete assistance to don bracxe or prosthesis.

WALK ON LEVEL

QUESTION: 11

A - Intact: Able to walk at least 500 metres, does not require a brace (orthosis) or prosthesis on leg, special adaptive shoes, a stick, crutches or a walking frame for this skill to be possible although some such aid may at times be used by choice.

B - Limited: Able to walk at least 500 metres, may need a brace or prosthesis on leg or the use of a stick, crutches, walking frame or special shoes. If there are locks on equipment, these are manageable, no assistance or supervision for safety or guarding is needed.

C - Helper: May be able to walk short distances within the house using a person, rails or furniture for support, but needs an assistant or supervisor for safety in this regard or for any walking in open space regardless of whether aids are used then.

D - Null: Walking is not possible or is unsafe at all times.

TRANSFER, CHAIR

QUESTION: 12

A - Intact: Able to approach, sit down and get up from a regular chair. If in a wheelchair, able to approach a bed or another chair, lock brakes, lift footplates and safely perform either a standing pivot or sliding transfer. Able to return safely changing the position of the wheelchair if necessary.

B - Limited: As above but requires adaptive or assistive devices such as a sliding board, or takes more than a reasonable time but needs no assistance.

C - Helper: Minimal lifting required and/or supervision for safety or cueing.

D - Null: Heavy lifting is required. Complete assistance given.

UP AND DOWN STAIRS, ONE FLIGHT

QUESTION: 13

A - Intact: Able to go up and down at least one flight of stairs without using any type of support and with safety.

B - Limited: Able to negotiate a flight of stairs with the use of the handrail or by using a stick or portable supports. No assistance needed.

C - Helper: Able to go up and down at least one flight of stairs but needs assistance or supervision for safety.

D - Null: Unable to go up or down one flight of stairs. Needs to be carried.

TRANSFER, TOILET

QUESTION: 14

A - Intact: Able to perform as in transferring to and from a chair with safety.

B - Limited: As above but requires adaptive or assistive devices such as grab rails or takes more than a reasonable time but does not need assistance.

C - Helper: Needs assistance for balancing or in adjusting clothes. Minimal assistance or lifting is required.

D - Null: Heavy lifting is required, complete assistance given.

TRANSFER, BATH/SHOWER

QUESTION: 15

A - Intact: Able to enter and leave a bath or shower recess safely.

B - Limited: As above but requires adaptive or assistive devices, such as grab rails, special seat or a lifter or takes more than a reasonable time.

C - Helper: Assistance, supervision or cueing given, minimal lifting involved.

D - Null: Heavy lifting required, complete assistance given.

WHEELCHAIR, 100 METRES

QUESTION: 16

A - N/A A wheelchair is not used.

B - Intact: Able to propel a wheelchair independently for at least 100 metres, must be able to go around corners, turn around, manoeuvre the chair to a table, bed, toilet etc. Is able to negotiate a 3% grade, manoeuvre on rugs, over low doorsteps etc.

C - Limited: As above but requires a powered wheelchair or takes more than a reasonable time or greater than 20 metres but less than 100 metres.

D - Helper: Needs assistance propelling a wheelchair.

E - Bed fast.

ARCHITECTURAL BARRIERS IN NORMAL RESIDENCE (CONSIDER ARCHITECTURAL PROBLEMS ONLY, NOT DISABILITY).

QUESTION: 17

A - Nil: There is access into and out of home, to all level if multi-storey, and to all rooms without safety hazard or requiring assistance. No potential future architectural barriers. Steps are minimal and wheelchair could enter residence.

B - Minor: As in "A" above, but some architectural barriers in non-essential areas, or future architectural barriers are probable, if a wheelchair were needed.

C - Unresolved: Major architectural barriers greatly increase dependence on others but are correctable.

D - Requires assessment.

SKIN (IN REFERENCE TO PRESSURE AREAS)

QUESTION: 18

A - Intact and no past problem from pressure damage.
B - Previous pressure ulceration but healed.
C - Current minor ulceration requiring treatment, or requiring assistance, e.g. four-hourly to relieve pressure areas.
D - Major or progressive skin lesion, requiring regular dressings.

ABILITY PROFILE (modified)
SCORE SHEET

Name ______________________________

Address ______________________________ Phone ____________

____

Date of Birth ______________ Assessment Date ____________

1(A)	2	3	4	5	6
(B)					
(C)					
7	8	9	10	11	12
13	14	15	16	17	18

Remarks: ______________________________

____

____

____

Name of Assessor ______________________________

ABILITY PROFILE

BARTHEL 1 - SCORES

		A	B	C	D	E
Q. 1	Bladder	10	10	5	0	
Q. 2	Bowel	10	10	5	0	
Q. 3	Dress Upper	5	5	3	0	0
Q. 4	Dress Lower	5	5	2	0	0
Q. 5	Grooming	5	5	0	0	
Q. 6	Care of Perineum	4	4	2	0	
Q. 7	Wash or Bathe	4	4	0	0	
Q. 8	Drink from Cup	4	1	0	0	
Q. 9	Feed from Dish	6	4	0	0	
Q. 10	Don a Brace	0	0	0	-2	

B.1 Maximum Total = 53

BARTHEL 2 - SCORES

Q. 11	Walk on Level	15	15	10	0	
Q. 12	Transfer, Chair	15	15	7	0	
Q. 13	Up/Down Stairs	10	10	5	0	
Q. 14	Transfer, Toilet	6	6	3	0	
Q. 15	Transfer, Bath	1	1	0	0	
Q. 16	Wheelchair - 100 metrs.*	0	10	5	0	0

B. 2 Maximum Total = 47

* Only scores if no score for Q. 11.

CARING LOAD

Q. 1	Bladder	0	0	0	10	
Q. 2	Bowel	0	0	5	10	
Q. 3	Dress Upper	0	0	2	5	1
Q. 4	Dress Lower	0	0	3	5	0
Q. 5	Grooming	0	0	5	5	
Q. 6	Care of Perineum	0	0	2	4	
Q. 7	Wash or Bathe	0	0	4	4	
Q. 8	Drink from Cup	0	2	4	4	
Q. 9	Feed from Dish	0	2	6	6	
Q. 10	Don a Brace				+2	
Q. 11	Walk on Level	0	0	5	0	
Q. 12	Transfer, Chair	0	0	8	15	
Q. 13	Up/Down Stairs	0	0	1	0	
Q. 14	Transfer, Toilet	0	0	3	6	
Q. 15	Transfer, Bath	0	0	3	5	
Q. 16	Wheelchair - 100 mtrs.	0	0	5	10	-5
Q. 17	Architectural Barriers	0	0	5	10	10
Q. 18	Skin	0	5	10	25	

NH5

Commonwealth Department of Health

APPLICATION FOR APPROVAL FOR NURSING HOME BENEFIT PURPOSES

National Health Act 1953

Nursing Homes Assistance Act 1974

1. Read the explanatory notes on the Form NH5A before completing this application.
2. Send the completed form to the Director, Commonwealth Department of Health, in the Capital City of the State in which application is made BEFORE admission to an Approved Nursing Home.
3. Please mark choice questions with a cross, e.g. ☒

TRANSACTION TYPE 1 – 3: P O 1

SECTION 1 – PARTICULARS (To be completed in BLOCK LETTERS by the patient or person applying on the patient's behalf)

PATIENT'S SURNAME 4 – 25: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

PATIENT'S FIRST GIVEN NAME 26 – 47: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

PATIENT'S SECOND GIVEN NAME 48 – 69: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

DATE OF BIRTH 70 – 77: ☐☐ / ☐☐ / ☐☐ (D D / M M / Y Y)

SEX: 78 ☐ MALE 79 ☐ FEMALE

MARITAL STATUS: 80 ☐ SINGLE 81 ☐ MARRIED 82 ☐ WIDOWED 83 ☐ OTHER

RACIAL ORIGIN

Is the patient an Aboriginal or Torres Strait Islander? 84 ☐ NO 85 ☐ YES

PENSIONER STATUS (If patient receiving a pension)

86 ☐ AGE 87 ☐ INVALID 88 ☐ REPATRIATION 89 ☐ OTHER

COMPENSATION/DAMAGES etc.

Has a claim been made, or is it intended to claim compensation or damages (Third Party, Workers' Compensation, etc.) in respect of nursing home treatment? 90 ☐ NO 91 ☐ YES

DOMICILIARY CARE

Has a person received Domiciliary Nursing Care Benefit on the patient's behalf within the last 12 months? 92 ☐ NO 93 ☐ YES

PATIENT'S ADDRESS (other than nursing home accommodating patient)

- -

- -

- -

- - - - - - - - - - - - - - -Postcode ....Telephone ....

NURSING HOME (Prepared to admit patient)

Name -

- -

Town/Suburb- - - - - - - - - - - - - - - - - - -Postcode ....

..../........./19.........

Signature of Patient (or person applying on patient's behalf) Date

OFFICE USE ONLY

PATIENT'S RESIDENCE AREA CODE

94 ☐ STATE 95–96 ☐☐ REGION 97–101 ☐☐☐☐☐ L.G.A.

NURSING HOME APPROVAL NUMBER 102–105 ☐☐☐☐ 106 ☐

PATIENT KEY TIE BREAKER 107 ☐

I.C.D. CODE 108–113 ☐☐☐☐☐☐

EMERGENCY ADMISSION 114 ☐ YES 115 ☐ NO

ADMISSION APPROVAL DATE 116–123 ☐☐ / ☐☐ / ☐☐ (D D / M M / Y Y)

SECTION 2 – PATIENT'S MEDICAL CONDITION (To be completed by Attending Legally Qualified Medical Practitioner.)

1. Mobility –

Able to walk –

unassisted .. .. ☐
with walking aid .. .. ☐
with help of another person .. .. ☐
Wheels self .. .. ☐

Able to get out of bed without help ☐
Chairfast .. .. ☐
Bedfast .... ☐

2. Incontinence –

Is patient incontinent? No ☐ Yes ☐

3. Care Required –

Needs non-professional supervision and personal care only .. .. ☐
Needs trained nursing attention .. .. ☐
Needs extra supervision (e.g. confused, wanders) ☐
Needs washing .. .. ☐
Needs professional rehabilitation .. .. .. ☐
Needs assistance at the toilet .. .. ☐

4. Diagnosis of major disabilities only..

5. Treatment (significant) and other remarks ....

....

I certify that the abovenamed patient has a continuing need for nursing care, and that the nature of his/her illness is such that admission to a nursing home is necessary so that the nursing care needed can be satisfactorily provided.

..../........./19.........

Medical Practitioner's Name (BLOCK LETTERS) Phone No. Signature Date

H1288 (7/84)

Commonwealth Department of Health

NOTIFICATION OF APPROVAL FOR NURSING HOME BENEFIT PURPOSES

National Health Act 1953
Nursing Home Assistance Act 1974

SECTION 1 – PARTICULARS (To be completed in BLOCK LETTERS by the patient or person applying on the patient's behalf)

PATIENT'S SURNAME	4 ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐ 25
PATIENT'S FIRST GIVEN NAME	26 ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐ 47
PATIENT'S SECOND GIVEN NAME	48 ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐ 69

DATE OF BIRTH 70 ☐☐/☐☐/☐☐ 77 (D D / M M / Y Y)

SEX 78 ☐ MALE 79 ☐ FEMALE

MARITAL STATUS 80 ☐ SINGLE 81 ☐ MARRIED 82 ☐ WIDOWED 83 ☐ OTHER

RACIAL ORIGIN

Is the patient an Aboriginal or Torres Strait Islander? 84 ☐ NO 85 ☐ YES

PENSIONER STATUS (If patient receiving a pension) 86 ☐ AGE 87 ☐ INVALID 88 ☐ REPATRIATION 89 ☐ OTHER

COMPENSATION/DAMAGES etc.
Has a claim been made, or is it intended to claim compensation or damages (Third Party, Workers' Compensation, etc.) in respect of nursing home treatment? 90 ☐ NO 91 ☐ YES

DOMICILIARY CARE
Has a person received Domiciliary Nursing Care Benefit on the patient's behalf within the last 12 months? 92 ☐ NO 93 ☐ YES

PATIENT'S ADDRESS (other than nursing home accommodating patient)

- -

- -

- -

- - - - - - - - - - - - - - - - Postcode .... Telephone ....

NURSING HOME (Prepared to admit patient)

Name -

- -

Town/Suburb - - - - - - - - - - - - - - - - - - Postcode ....

..../....../19......
Signature of Patient (or person applying on patient's behalf) Date

OFFICE USE ONLY

PATIENT'S RESIDENCE AREA CODE	94 ☐ STATE 95 ☐ 96 ☐ REGION 97 ☐☐☐☐☐ 101 L.G.A.
NURSING HOME APPROVAL NUMBER	102 ☐☐☐☐ 105 106 ☐
PATIENT KEY TIE BREAKER	107 ☐
I.C.D. CODE	108 ☐☐☐☐☐☐ 111
EMERGENCY ADMISSION	112 ☐ YES 113 ☐ NO
ADMISSION APPROVAL DATE	114 ☐☐/☐☐/☐☐ 121 (D D / M M / Y Y)

I am satisfied that by reason of infirmity or illness, disease, incapacity or disability, the patient requires such nursing care as would warrant his admission to an approved nursing home YES ☐ NO ☐

If the answer to the above is yes I am satisfied that the needs of the patient would be adequately, and more suitably, provided for in accommodation in an institution other than an approved nursing home and that such accommodation is available to the patient YES ☐ NO ☐

Approval has/has not been given for the above named patient to be admitted to an approved nursing home. This approval for admission remains current for 90 days from ..../........./19. .... Advice of this approval has been forwarded to the patient named in the application form.

for MINISTER FOR HEALTH

EXPLANATORY NOTES

1. For the purpose of the National Health Act and the Nursing Homes Assistance Act *'nursing home care'* means accommodation and nursing care of a kind provided in a nursing home. *'Nursing care'* means nursing care by or under the supervision of a registered general nurse.
2. The identification of patients as Aboriginal or Torres Strait Islander is for statistical purposes only.
3. ***Person Applying on Patient's Behalf:*** This application should only be signed on the patient's behalf when the patient is unable to sign.
4. The patient must be admitted to a nursing home within 90 days after the date of approval by the Minister for Health, otherwise the approval shall lapse.
5. The attending Medical Practitioner may forward this application direct to the Director, Commonwealth Department of Health, if considered necessary.
6. For further information, telephone or write to the Director, Commonwealth Department of Health, in the Capital City of the State in which you reside.

Appendix C

Attendant Management Manual

ATTENDANT
CARE
PROJECT

THE ATTENDANT CARE PILOT STUDY:

ATTENDANT MANAGEMENT

Finding Attendants

1) Cost-free:

- University/College Noticeboards
- Local Council Noticeboards/Community Service Noticeboards
- Hospital Noticeboards
- Health Care Agencies
- Friends who use attendants
- Local Church
- Welfare Agencies
- Local C.E.S. Office
- Charitable Organizations
- Local Shop Windows
- Local Home Care Office
- Talking to neighbours

2) Other sources :

- Advertising in local newspapers

Interviewing

1) Prior to the interview...

- Prepare a duty statement
- Prepare a timetable setting out your routine
- Think about the qualities you are looking for in an attendant.

  For example:
    - ability to accept responsibility
    - willingness to work closely with others.
    - ability to relate well to others.
    - willingness to learn job well.
    - physical skills for lifting, bending and reaching - you do not have to be a strong person to be a good attendant.
    - clean personal habits.

2) What do you need to ask Attendants ?

- Preliminary interviews can be done by telephone and avoid you having to personally interview someone who does not want to be involved in personal care or who lives too far away to be a regular attendant.
- Has he/she done this type of work before?
  Discuss each item on the duty statement.
- Does he/she have a back problem?
- Do you require information about his/her health, or driving record?

- How often does he/she want to work? Are there any times when he/she will not be available - weekends, nights? Knowing this information will enable you to roster people according to times that will not conflict with their personal/social arrangements.
- Does he/she live close to you?
- Does he/she have access to reliable transport?
- Do you require references or referees?

- * Do you wish to have a trial period to establish personal compatibility - or his/her competence?
- * Does he/she wish to observe your personal care being done by your current attendant prior to making a decision about being your attendant?
- * Does he/she need some instruction that you cannot provide? If so it can be arranged for them to attend an agency where they can be shown appropriate procedures (bowel care, chest care, urinary care, safe lifting methods etc.)
- *** Does the person realize that they need to be reliable and punctual and the implications for you if they are not?

N.B.

- * You will need more than one attendant
- * Attendants should be able to be contacted by telephone.
- * Have confidence that you will find someone who is appropriate.

  Don't employ someone with whom you are not happy or who appears to have his own personal problems, since it makes a poor working relationship.

3) What will Attendants ask you ?

* Payment of Wages:

You will need to decide how often you will pay your attendants (Your allowance will be issued on a fortnightly basis)
It is imperative that you keep accurate records of the hours your attendants work.
Wages: $7.51/hour plus $1.00/hour travel allowance

* Worker's Compensation:

As an employer you are obliged to take out an insurance to cover your attendants.
CONTACT: Brian McAuley
Ph.
389 1144
at the Government Insurance Office. He will be able to assist you with any enquiries.

* Other Provisions:

Since your attendants are 'casual' employees there are NO provisions for sick leave, sick pay, holiday pay or long service leave.

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Rights and Responsibilities

... of the employer

- Be as complete and honest as possible in explaining your needs.
- Do all that is feasible for you to do for yourself.
- Do not ask your attendant to do more than the duties which he/she has agreed to do.
- Be ready when your attendant is scheduled to arrive.
- Don't ask your attendant to stay longer than necessary. If you need to reschedule hours to complete daily tasks, be as flexible and considerate as possible.
- Be as courteous and thoughtful as possible at all times.
- Be as open as possible in your communication.
- Give feedback to your attendant as constructively as possible.
- Be aware of available back-up personnel.
- As an employer you are responsible for taking out insurance to cover your attendants against accidents that may occur. Your local G.I.O. can provide you with information on how to go about this.
- The paperwork attached to being an employer is your responsibility and you should organize a system whereby you have concise records of any payments you make to attendants.
- Advise appropriate agencies (Home Care/District Nursing) of your participation in pilot study and change your arrangements with them as necessary.

... of the employee

- To resolve questions regarding the job as much as possible prior to beginning work.
- Arrive at the scheduled time ready to work.
- Notify employer if he is going to be more than 10 minutes late for any reason.
- Notify employer as soon as possible when he cannot come.
- Schedule time off as far in advance as possible.
- Complete duties as well as possible within the time constraints.
- If duties cannot be performed in an efficient manner in the time allocated, he should negotiate with employer to decrease duties or increase time allocated for duties.
- Maintain record of number of hours worked.
- Be as courteous and thoughtful as possible.
- Be open in communication with employer.
- Give feedback as constructively as possible to employer.
- Respect the privacy of the employer and maintain confidentiality and professional behaviour.
- Be aware of responsible actions if a medical emergency should occur.

Drawing up a Contract

Do you wish to have a formal/verbal contract outlining:

(a) duties of the attendant.

(b) hours to be worked.

(c) notification procedure for when an attendant is unable to work?

The advantage of a written contract is that it enables the employer to clearly outline what the attendant is required to do and when he should be doing it. Having an agreement in writing may help avoid confusion about responsibilities, working hours and eliminate the possibility of the employer or employee taking liberties or making unreasonable requests. The contract can be referred to in instances of disagreement or misunderstanding. In addition, in the case of any legal action (worker's compensation case) your employer/employee relationship and the duties involved are clearly stated.

Rosters : Regular and Emergency Planning

- In planning a roster you will need to consider not only what your current needs are, but how your needs may alter in the short term.

- Design your initial roster to cater for someone who is a slow, careful worker - it can be reduced later if necessary.

- Emergency arrangements are best arranged with people who do not want to be a regular attendant but who will be available at short notice on an infrequent basis. It is essential that emergency attendants have a telephone.

- It is important to date all rosters.

- Rosters will need to be reviewed as your needs change. This should be done in consultation with your attendants.

- The handicapped individual should be as independent as feasible and should expect the attendant to do only those activities which it is not realistic for the handicapped individual to do without assistance. This will help limit the time which the attendant actually worked and make the use of the attendant more efficient.
  The handicapped individual and the attendant should negotiate details of their work arrangement together.

- Draw up a list of names, addresses and telephone numbers of attendants.

The Attendant's Perspective

* What are the positive aspects of being your attendant?

* What are the negative aspects of being your attendant?

* Learn to recognize the signs of "burn-out": indifference, arriving late, leaving early, appearing resentful about doing tasks that were previously done willingly.

* If you are unhappy with an attendant's work or attitude to work it is _your_ responsibility to do something about it. It is important to be tactful in order to avoid conflict or an argument. Remember that attendants often know other attendants and any unpleasantness may make it difficult for you to find someone else to do your personal care.

* Dismissal is your responsibility. If you dismiss an attendant make sure that he clearly understands the reasons for it.

* You will need to notify the co-ordinator in the instance of dismissal of an attendant.

* For the duration of the pilot study, the research team will need to know:
  - (a) the number of attendants you employ at any one time.
  - (b) the circumstances and reasons for dismissal.

You will be issued with information cards on which to record this information.

* Facts about the Pilot Study

It is important to understand that the Attendant Care Pilot Study is a research project. This necessitates the Senior Research Assistant contacting you and your attendants from time to time.

The project has only been funded for a two year period and your allowance will continue for this period only, unless a decision about the future of Attendant Care is made prior to the expiry of the two year period.

In the instance of any problems arising during the course of your participation in the project, the co-ordinator is available to help you:

DONNA PERCY
28 WARATAH AVE
RANDWICK. 2031
PH. 398 8495 (WORK)
327 5571 (AFTER HOURS)

Appendix D

Sample of Advertisements used to find Attendants

PERSONAL CARE ATTENDANT

is required by a young man with a physical disability, to assist him in preparing for work in the mornings, 1 hour 6.30-7.30am, also for 1 hour in the evenings - time negotiable.

COULD SUIT STUDENT
398 8495

Manly Daily
10/9/85

PERSONAL CARE ATTENDANT

is required by a young woman with a physical disability to assist her at the weekend for 1 1/2 hours each day - time negotiable. $8 per hour. Narraweena area.

981 4958 week-ends
398 8495 week-days

ATTENDANT FOR DISABLED PERSON

Punchbowl area, to work 2-3 hours per day, 5 days a week. Experience not necessary. Training available. Phone 398 8495.

Appendix E

Assessment

Summary of Disability Profile, Colville (1984)

A total of up to seventy-two items can be rated according to four basic levels of function:

Independent

A - normal or near normal function.
B - may be some difficulty experienced.

Assistance required

C - some help needed for function.
D - function is substantially dependent on role of helper.

Areas of function rated include:

Limb Function:	spasticity/flaccidity ataxia/tremor sensation splints required
Bladder/bowel:	continence
Walking/mobility:	equipment used transfers stability (falls)
Personal Care:	dressing washing grooming drinking/eating skin care
Communication:	language spoken speech skills hearing
Cognitive Skills:	memory problem solving

Respect for self and others

Occupational ability and status

Financial status

Family/social support

Accessibility of usual environment

Medical status

Vision

From certain of the ratings made, scores computed are:

- Kurtzke Functional System
- Barthel Score
- Nursing Load
- Disability Rating
- Day Care Load

The printout sheet is used to give a profile which can be used both to identify individual needs and outcomes and in providing group data to plan overall service delivery.

SAMPLE: INITIAL APPLICATION FORM

Administrative Details.

Assessment of Attendant Care Needs

Circle your requirements for assistance in: (refer to rating guidelines)

Self-Care

Urinary Care	A	B	C	D
Bowel Care	A	B	C	D
Dresing - upper body	A	B	C	D
lower body	A	B	C	D
Grooming	A	B	C	D
Toilet	A	B	C	D
Showering/bathing	A	B	C	D
Drinking	A	B	C	D
Eating	A	B	C	D
Fitting brace or prosthesis	A	B	C	D
Skin Care	A	B	C	D

Mobility

Walking - level	A	B	C	D
stairs	A	B	C	D
	A	B	C	D
Transfers - chair	A	B	C	D
toilet	A	B	C	D
bath/ shower	A	B	C	D
Environment	A	B	C	D

Estimate of weekly time requested for self-care, mobility.......

Other Assistance Requested:

Housework

Meal Preparation

Shopping

Garden Maintenance

Driving

Other, please specify

Estimate of weekly time requested for other assistance..........

Rating Guidelines
(Take from Appendix B).

Appendix F

Costs

TABLE F.1

INSTITUTIONAL COSTS

Australian Housing Research Council Data
Adjusted to 1984/85

Costs ($) per patient day

A. Capital Costs

Type of Institution	Land	Buildings	Plant & Fittings	Total
Hospitals	3	38	8	49
Nursing Homes	1	10	4	15
Specialized Institutions	1	11	4	16
Hostels	3	12	1	16

B. Operating Costs

Type of Institution	Accom & Meals	Medical	Param.	Pers. Care	Home Care	Admin.	Total
Hospitals	76	16	4	8	38	8	151
Nursing Homes	31	1	1	4	16	3	57
Specialized Institutions	31	1	19	8	16	3	79
Hostels *	4	15	11	1	7	3	41

* Residential accommodation with full time health care professional staff

TABLE F.2

DOMICILIARY COSTS
(per person day)

Australian Housing Research Council Data
Adjusted to 1984/85

Costs ($) per person per day

A. Capital Costs

Type of Accommodation	Land	Buildings	Plant & Fittings	Total
Rented single (1 person)	NA	NA	NA	12
Normal c spouse (2 people)	4	10	3	16
Modified c Family (4 people)	3	7	3	11

B. Operating Costs

Type of Accomm.	Accomm/ Meals	Medical	Param.	Pers. Care	House Care	P'chased Meals	Total
Unit:	Per Person Day	Per Visit	Per Visit	Per Hour	Per Hour	Per Day	
Rented Single	3	15	11	8	7	4	48
Normal with spouse	5	15	11	8	7	4	50
Modified c family	7	15	11	8	7	4	52

Appendix G

Home Care Service of N.S.W.
Survey Responses

WHO INTERVIEWS/SELECTS PERSONAL CARE AIDES?

SUMMARY OF RESPONSES

* A Branch may be counted against more than one response

RESPONSE	NUMBER OF BRANCHES GIVING RESPONSE
Aides employed specifically for a given client	4
Aides employed who had been suggested by a client	4
Preference given to people with nursing training and/or experience	13
Would be willing to employ people suggested by a client but have not done so yet	10
Aides for new clients usually selected from existing set of aides	12
All aides do personal care work as required	4
Only certain aides do personal care work	11
Clients have the chance to reject co-ordinator's choice of aides	11

WHO TRAINS THE PERSONAL CARE AIDES?

SUMMARY OF RESPONSES

* A Branch may be counted against more than one response

RESPONSE	NUMBER OF BRANCHES GIVING RESPONSE
Community/district nurses ("on the job")	7
No training needed because if possible nurses are employed for PC work	9
Co-ordinator, assistant co-ordinator or a Branch Committee member is a trained nurse - gives "on the job" training	6
Special arrangement with a local hospital, nursing home or rehabilitation centre - aides sent individually for specific tasks	13
New aide replacing an existing aide is trained by that aide for the specific clients involved	4
** Clients do any training required	14
Will not put untrained aides in to do PC - must be "properly" trained first	2
Will not do "nursing" PC	1

** Although many branches mentioned clients as a possible source of training, some emphasised it strongly and some felt nothing else was required.

WHAT ADDITIONAL SERVICES DO DISABLED CLIENTS NEED?

SUMMARY OF RESPONSES

* A Branch may be counted against more than one response

Branches fall into two main groups on this issue:

- HCS aides can do whatever is required: no other services required really.
- Should not be duplication of services in an area: would help to arrange alternatives for certain tasks if possible, e.g., meals on wheels, transport, home maintenance by volunteers, etc.

RESPONSE	NUMBER OF BRANCHES GIVING RESPONSE
HCS alone	12
HCS plus other services	8
District/Community Nurses required for medical tasks such as catheters and enemas	5
District/Community Nurses "keep an eye on things"	2
Some disabled clients really need a nursing home	1

WHAT ARE THE BIGGEST PROBLEMS YOU ENCOUNTER IN CO-ORDINATING A PERSONAL CARE SERVICE FOR THE DISABLED?

SUMMARY OF RESPONSES

* A Branch may be counted aginst more than one response

RESPONSE	NUMBER OF BRANCHES GIVING RESPONSE
Requires a relatively greater amount of Co-ordinator/office time per client. Staffing formula should allow for this	10
Finding and retaining suitable staff who will work "out of hours"	18
Worry that insufficient hours in future if too many severely disabled clients	4
Insufficient trained aides for the work the Community Nurses want us to take on	1
The worry of knowing a disabled person living alone is totally dependent on home care aides	2
Some clients have become too demanding and ring aides at all odd hours etc.	1
Finding enough disabled clients	3
Not right to have unskilled staff have to bear responsibility for medical work	1
No problems	5

DOES THE BRANCH ACTIVELY SEEK OUT PEOPLE IN THE AREA WHO MAY NEED PERSONAL CARE ASSISTANCE?

SUMMARY OF RESPONSES

* A Branch may be counted against more than one response

RESPONSE	NUMBER OF BRANCHES GIVING RESPONSE
Responds to requests to give talks to local groups	6
Actively seeks to contact local doctors, hospitals, organisations	10
Advertise in local newspaper to show all the HCS services	6
No using up all hours just responding to referrals	16
No open advertising for fear of not being able to meet the requests for service	3
Seek out disabled people when hear of them in the area	2

Many mentioned that Education Officers temporarily attached to the Branch had sought out disabled people who could use the service, but must have not continued the seeking out.

Appendix H

Research Brief issued by the Department of Community Services

RESEARCH BRIEF FOR A PILOT ATTENDANT CARE PROJECT

The Commonwealth Government has allocated funds for a pilot project on attendant care for severely disabled people. The pilot will be conducted in New South Wales; negotiations are proceeding for it to be administered through the Home Help Service of New South Wales. There is a possibility that a second minor pilot study will be mounted in another State.

Definition of Attendant Care

The concept of attendant care has been defined, for the purposes of the pilot, as the provision of assistance with key personal care tasks such as bathing, dressing and toiletting to severely handicapped people. Participants in the pilot will be those requiring between two and four hours of such assistance per day. These people will also be in the broad working age group and have reasonably stable medical conditions.

Attendant care will be provided to enable such people to live more independently in the community either by moving to less institutional living arrangements, eg. shift from a nursing home to live in the community or enabling them to stay in less restrictive arrangements. High priority will be given to severely handicapped people who are in employment or vocational training or who have reasonable employment prospects.

Objectives

The need for a pilot became evident during extensive investigations of overseas schemes and local conditions. It became clear that there was insufficient information upon which to gauge potential client groups, their particular attendant care needs and how these needs might best be met. The following objectives for the pilot were therefore defined:

a. to test claims that attendant care will enable severely physically handicapped people to live more independently in the community;

b. to assess various options on how this attendant care might most effectively be provided; and

c. to test claims that an attendant care scheme will:

   (1) facilitate a higher quality of life amongst severely physically handicapped people; and

   (2) together with existing community services, provide a less costly system of appropriate support services to severely handicapped people, than existing institutional arrangements.

Elements of the Pilot Project

In order to achieve these objectives, three major groups will be involved in the conduct of the pilot. The groups will be:

a. An Assessment Unit. Under advice from the research body engaged to evaluate the project, the Unit will be responsible for the selection of participants, assessment of their attendant care needs and the degree to which their independence is enhanced by attendant care. The Unit will be responsible for monitoring any changes in these areas for the duration of the pilot. The Unit will need to unsure that persons selected to participate in the pilot are already at their maximum level of independent functioning, i.e., the function of attendant care will be to meet residual short-falls in independent living. Those who are not functioning at their maximum independent level will be referred to an appropriate rehabilitation agency, as attendant care is not to be provided in lieu of rehabilitation.

   The Unit will comprise a full-time occupational therapist and administrative assistant. It will call upon additional professional expertise such as vocational counselling from the Commonwealth Rehabilitation Service as necessary. It will also be able to call on assistance from an experienced attendant, and a handicapped person with experience in attendant care. The Unit may provide additional assistance to the Home Help Service in regard to training of attendants and handicapped participants.

b. Home Help Service of New South Wales. The Executive Council of Home Help Service, a voluntary organisation, has expressed agreement to being responsible for the administration of the delivery of attendant care. A Co-ordinator employed by the Service under the project, will be responsible for the oversighting of service delivery to approximately twenty-eight participants as well as the co-ordination of existing community services required by participants.

   The Home Help Service will be responsible for the delivery of two forms of attendant care assistance:

   (1) The provision of attendant care services to some participants. This will incorporate a measure of consumer control over choice of attendants, and the time of the day at which the attendant care is delivered.

   (2) The provision of an attendant care "allowance" to other participants with which to directly pay their own attendants. Participants will have the power to hire and fire their own attendants. Attendants will, however, be formally contracted from the Home Help

Service which will provide the range of backup support necessary. This support will include the provision of relief attendants and assistance with respect to employer responsibilities etc.

These two forms of attendant care assistance will be provided in three settings:

- A person who lives alone.
- A person who is the sole person requiring attendant care in a household (eg lives with spouse or family, i.e. has an existing support network at place of residence).
- Group settings such as group homes run by voluntary organisations, where one, or more than one, person requires some form of attendant care.

A possible second phase of the pilot is the provision of domiciliary respite care, covering both planned, occasional relief and emergency attendant care as necessary for people living with their families.

c. Research Group. The research group will have a number of research aims arising from its general role of undertaking measurements and analyses associated with fulfilling the pilot's objectives:

(1) In respect of the first objective,

> "to test claims that attendant care will enable severely physically handicapped people to live more independently in the community",

the research group will need to analyse whether attendant care is the only missing key to independent living for severely handicapped people. This will involve the documentation of any barriers to independent living by a lack of support or disincentives and the nature of additional supports or incentives required to overcome these problems. It will also involve the measurement of gains participants make in independent living capacity.

(2) The second objective of the pilot is:

> "to test various options on how this attendant care might most effectivly be provided".

The research group will be required to gather information about the process of providing attendant care and the possible forms in which it could be provided. This will include a detailed comparison of the advantages of the service and "allowance" based modes for people with different levels and types of disability. The group will also undertake critical documentation of the pilot including such matters as:

- how attendants were recruited and trained;
- the characteristics of attendants and their turnover rates;
- the formal and informal activities undertaken by the co-ordinator, and what proportion of his/her time was taken up on each major activity;
- reliable assessment and reassessment scales and indexes of independent functioning;
- the most appropriate mechanisms for assessment;
- any changes that occurred in assessment and administrative procedures during the pilot;
- clients' satisfaction with assessment and service delivery procedures (such as client selection, quality of care provided); and
- any variation in the level of attendant care needed by participants according to living arrangements.

(3) the third objective is:

> "to test claims that an attendant care scheme will:
>
> (i) facilitate a higher quality of life amongst severely physically handicaped people; and
>
> (ii) together with existing community services, provide a less costly system of appropriate support services to severely handicapped people, than existing forms of institutional arrangements."

Part (i) will involve measurement of changes in the quality of life experienced by participants. Part (ii) will involve a comparison of the costs associated with institutional living and community living with attendant care. Two particularly important matters in this area are the difference in the total cost of the two living arrangements and the difference in the cost structure in each setting, including who bears each of the major costs in each setting (is it Commonwealth or State Government, voluntary agencies or severely handicapped individuals?).

There will be a number of general tasks associated with fulfilling all objectives. One will be sample selection, to ensure representativeness of type and levels of severe disability. It may be appropriate for a control group to be introduced in relation to the research component of the pilot.

It is expected that the final report of the pilot will also include case study material as well as recommendations regarding the creation of a national scheme.

To successfully undertake the research component, the researchers will have to work closely with the Assessment Unit and the Co-ordinator of the Service.

Employment of Researcher

The research should be undertaken by an individual or group external to the Assessment Unit and Home Help Service.

The research body will be employed for a two to two and a helf year period from January/early February 1983, although the pilot attendant care assistance will only be provided for two years from March 1983.

The initial allocation for conducting the pilot 1982-83 is $100,000; however, the Minister for Social Security has agreed that a two-three year pilot is appropriate. Should a second pilot be undertaken, it would not commence until next financial year and funds in addition to those allocated for the New South Wales pilot would have to be provided for its conduct. An "in principle" agreement to the evaluation of the second pilot by the research group is, however, needed.

It is seen as important that the researchers, Assessment Unit and the Co-ordinator should begin lead up activities at least six weeks before the actual pilot begins and that the research body may need additional time after the pilot is completed to write a final report. The Assessment Unit, the Co-ordinator and the research group will report to a Steering Committee comprising representatives of the Australian Council for Rehabilitation of Disabled, the National Advisory Council for the Handicapped, a consumer representative, and the Department of Social Security, including the Social Welfare Policy Secretariat.

Based on previous experience it is expected that the equivalent of one to one and a half full-time researchers with relevant experience will be needed to complete the research.